TRAUMATIC STRESS SYMPTOMS ACROSS PEDIATRIC CHRONIC ILLNESS

By

LISA M. INGERSKI

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2008

© Lisa M. Ingerski

To my family for all their support.

ACKNOWLEDGMENTS

I would like to thank the chair of my committee, David M. Janicke, Ph.D., for his support and mentorship. I would also like to thank the members of Dr. Janicke's lab, who offered their time and assistance; and Kimberly Shaw, Ph.D. and the other professionals at each of the clinics who helped make recruitment for this study possible. Lastly, I would like to acknowledge the other members of my committee: Stephen R. Boggs, Ph.D., Fonda Davis Eyler, Ph.D., and Michael E. Robinson, Ph.D.

Funding for graduate training was provided by the National Institute of Child Health and Human Development (NICHD) through a pre-doctoral fellowship award titled "Training in Treatment Outcome Research for Child Populations." This study was also supported by a grant from the Center for Pediatric Psychology and Family Studies in the Department of Clinical and Health Psychology at the University of Florida.

TABLE OF CONTENTS

page

LIST OF TABLES

Abstract of Dissertation Presented to the Graduate School
of the University of Florida in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy

TRAUMATIC STRESS SYMPTOMS ACROSS PEDIATRIC CHRONIC ILLNESS

By

Lisa M. Ingerski

December 2008

Chair: David M. Janicke
Major: Psychology

Chronic health conditions impact a significant number of children and adolescents in the United States and are associated with significant psychosocial concerns as youth and their families cope with and adjust to the child's illness. Previous researchers have recently proposed a framework of traumatic stress to describe the psychological functioning of these families; however, few studies exist that directly compare traumatic stress symptoms across different pediatric disease groups. The current study compared the traumatic stress symptoms of youth and their parents across pediatric transplant, HIV, and sickle cell disease groups and examined possible predictors of traumatic stress symptoms in these populations. Researchers found significant differences in traumatic stress symptoms such that pediatric transplant candidates reported greater symptoms than youth diagnosed with HIV by child self-report. Children reported significantly greater traumatic stress symptoms by self-report than by parent-proxy report of child symptoms across groups. While parent traumatic stress symptoms did not predict child symptoms, children who experienced longer hospitalizations experienced fewer traumatic stress symptoms by child self-report and children with greater functional impairment experienced greater symptoms by parent-proxy report. Additional analyses exploring the functioning of pediatric transplant candidates found that the quality of life and family

functioning of transplant candidates was lower than that reported in the healthy population, but that their overall functioning was similar to other chronic illness groups. These findings suggest that a model of traumatic stress addresses the needs of families across pediatric conditions and describes individuals reporting both clinical and sub clinical levels of distress.

CHAPTER 1
INTRODUCTION

Although prevalence rates vary, there is little disagreement that chronic illness affects a significant number of children and adolescents in the United States. Recent national data suggests that up to 19.3% of children have special health care needs in the United States (Bethell, Read, Blumberg, & Newacheck, 2008) while an earlier survey suggests that as many as 31.5% of adolescents in the United States report having one or more chronic health conditions (Newacheck, McManus, & Fox , 1991). These numbers, while impressive, only begin to describe the significant burden families of chronically ill youth face. In addition to practical concerns, such as financial difficulties (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004) and increased health care usage (Newacheck & Halfon, 1998), youth and their parents also face significant psychosocial difficulties as they cope with a pediatric chronic illness.

Recent reviews suggest that both chronically ill youth and their parents experience significant psychosocial symptoms while they cope with and adjust to a particular pediatric disease. While the majority of researchers find that youth and their parents do not experience clinically significant symptomatology, findings continue to show that both groups report a number of symptoms of distress and/or impairment (Barlow & Ellard, 2006; Geist, Grdisa, & Otley, 2003; Lewis & Vitulano, 2003; Boekaerts & Röder, 1999). For example, chronically ill children exhibit greater internalizing and externalizing symptoms (Lavigne & Faier-Routman, 1992) and poorer adjustment (Stein, Westbrook, & Silver, 1998) compared to their healthy peers. Similarly, parents report significant stress (McClellan & Cohen, 2007) and mood impairment (Cadman, Rosenbaum, Boyle, & Offord, 1991) across various different pediatric chronic illness groups. Not surprisingly, these findings are not just unidirectional. Often, child and parent

psychological functioning is related such that the functioning of parents affects that of their children (Kazak & Drotar, 1997; Lavigne & Faier-Routman, 1993).

The psychosocial difficulties youth and parents face are important not only in themselves, but also because they are related to children's adherence to treatment following diagnosis (Fotheringham & Sawyer, 1995). While adherence across pediatric populations is generally poor, usually estimated at approximately 50% (Winnick, Lucas, Hartman, & Toll, 2005; Osterberg & Blaschke, 2005; Jay, Litt, & Durant, 1984), adherence is often worse when youth and their parents are facing psychosocial difficulties. Previous researchers found that chronically ill children's psychosocial adjustment was related to both functional status (Stein & Jessop, 1984) and adherence to medical recommendations (Smith & Shuchman, 2005). In the widely studied pediatric asthma and pediatric diabetes populations, researchers found a number of different psychosocial factors related to child adherence. For example, researchers studying these two groups found that child depression, peer victimization, and externalizing behavior problems were significantly related to children's adherence (Storch et al., 2006; Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004).

In addition to their own psychosocial difficulties, youth's adherence to treatment is also related to parental adjustment and general family functioning. In a review of the literature, Fiese and Everhart (2006) found that better family functioning (i.e., greater cohesiveness, more positive interactions) was related to improved adherence across various pediatric chronic illnesses. For example, researchers previously provided support for the importance of parent and family factors such as maternal depression in pediatric asthma (Bartlett et al., 2004) and maternal involvement, family cohesion, and general family functioning in pediatric diabetes (Lewin et al., 2006; Wiebe et al., 2005; Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004).

While the adherence literature summarized above clearly documents important relationships between psychosocial factors and adherence in pediatric chronic illness populations, researchers have also begun to examine the direct relationship between psychosocial factors and survival. Although the findings are mixed, researchers examining pediatric bone marrow recipients found that several factors, including poor family functioning, paternal psychopathology (McConville et al., 1990) and prognosis (Dobkin et al., 2000) were related to unexpected survival following transplant. Furthermore, Dobkin and colleagues found that those families with the poorest prognosis also reported the most marital difficulties and, regardless of prognosis, reported more stress than parents of healthy children (Dobkin et al.).

While these studies help to illustrate the need for appropriate psychological intervention to help youth and families cope with a stressful health condition, few well-validated treatment options are currently available in the pediatric population (Lemanek, Kamps, & Chung, 2001; Barlow & Ellard, 2004; Plante, Lobato, & Engel, 2001). Research that examines psychosocial functioning, adherence, and possible interventions in chronically ill pediatric population remains relatively new compared to adult populations and lacks a cohesive framework to thoroughly explain youth's functioning. Unfortunately, while research in adult populations provides promising models to guide investigators' work, simply examining the adult chronic illness literature is not enough. Chronically ill children and adolescents face unique developmental issues that affect both their medical and psychological functioning and make it difficult to directly apply studies of chronically ill adults directly to the pediatric population. Differences in pharmacotherapy and other treatment regimens, physical, cognitive, and emotional development, and differences in adherence rates between pediatric and adult populations each make findings in the adult literature difficult to apply to pediatric populations (Hsu, 2005; Streisand & Tercyak,

1995). Given these important differences and the relative lack of established interventions for pediatric chronic illness, researchers have advocated for a single theory or framework to guide future research and intervention work in the area of pediatric chronic illness (Barlow & Ellard, 2004).

Traumatic Stress

While the previous literature summarized above demonstrates the relationship of psychosocial functioning to the adherence and survival of chronically ill children and adolescents (Smith & Shuchman, 2005), current research lacks a single model or framework from which to understand the impact of pediatric illness on the psychosocial functioning of the family as a whole. Given the current lack of well-established interventions in the pediatric chronic illness population (Lemanek et al., 2001), the use of a comprehensive model of psychosocial functioning may help clinicians to develop appropriate interventions for a variety of pediatric chronic medical conditions. Central to creating a coherent picture of the psychosocial functioning of chronically ill youth and their parents is identifying a single, comprehensive psychological model that adequately addresses the psychosocial difficulties youth and their families face. It is in this light that the current study sought to examine a model of traumatic stress as an informative framework to describe the psychosocial functioning of youth and parents across three separate chronically ill pediatric populations.

Other researchers have recently used a model of traumatic stress to describe the functioning of pediatric populations and their families. This model of traumatic stress originates in the Posttraumatic Stress Disorder (PTSD) literature. PTSD, a well-established psychiatric diagnosis, is associated with a number of unique emotional and cognitive symptoms that cause significant interference in a person's daily functioning. A diagnosis of PTSD requires the presence of symptoms from three primary symptom clusters: (1) re-experiencing a traumatic

event, (2) avoidance of stimuli associated with a traumatic event, and (3) persistent arousal symptoms (American Psychiatric Association, 2000). In contrast to the dichotomy inherent in meeting an actual diagnosis of PTSD (i.e., a person has the symptoms required for a diagnosis or not), a model of traumatic stress provides for individuals to fall across a continuum of PTSD symptomatology where individuals can exhibit few or many traumatic stress symptoms. This continuum may be especially informative in pediatric populations. Although only a minority of youth and parents meet the criteria for a diagnosis of PTSD, evidence suggests that up to 80% of children and families experiencing illness or injury experience traumatic stress symptoms (National Traumatic Stress Network, 2005). For example, in a community sample of adolescents, most youth who reported experiencing a traumatic event also reported experiencing traumatic stress symptoms (Cuffe et al., 1998). In other words, a model of traumatic stress allows for a cohesive description of the difficulties an individual may face by describing both a person exhibiting few traumatic stress symptoms and one meeting diagnostic criteria for PTSD. By providing a continuum of PTSD symptoms, such a model may help to better understand the psychosocial functioning of chronically ill youth and their families. In addition, such a model may allow for a more cohesive and concise description of the difficulties these families face.

Although this model has only recently been applied to pediatric populations, researchers studying pediatric cancer and pediatric injury have begun to use a framework of traumatic stress to further their understanding of the psychological impact of these conditions on youth and their families (Barakat, Alderfer, & Kazak, 2006; Best, Streisand, Catania, & Kazak, 2001; Kazak; Alderfer, Streisand, et. al., 2004; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Rourke, Stuber, Hobbie, & Kazak, 1999). Examining PTSD symptoms in parents, researchers found that up to 21% of parents reported symptoms of PTSD consistent with a diagnosis two months

following their children's discharge from the pediatric intensive care unit (Balluffi et al., 2004). Likewise, examining PTSD symptoms in youth, researchers found that approximately 20% of young adult cancer survivors report symptoms consistent with a diagnosis of PTSD at some point following the end of treatment (M = 11 years following treatment; Hobbie et al., 2000) while almost 70% of children experienced mild PTSD symptoms immediately following acute injury (Schreier, Ladakakos, Morabito, Chapman, & Knudson, 2005).

In addition to summarizing overall psychological functioning, a framework of traumatic stress also provides a possible means of intervention in pediatric populations. For example, researchers have outlined a model of prevention in which traumatic stress symptoms can be addressed within the medical setting (Stuber, Schneider, Kassam-Adams, Kazak, & Saxe, 2006). This model involves three levels: (1) providing general support for families who are coping well with a distressing event (i.e., families where members exhibit no or few PTSD symptoms), (2) providing extra support to families who are distressed or at risk for further psychosocial difficulties (i.e., family members report symptoms of PTSD but do not meet diagnostic criteria), and (3) psychological support for the small number of families demonstrating significant distress (i.e., families where a member may meet diagnostic criteria for PTSD). This model meets both the needs of families coping well with a traumatic event or illness as well as families having significant psychosocial difficulties (e.g., traumatic stress). In addition, the model provides suggestions for how medical professionals can appropriately intervene to help improve the psychosocial functioning of families during that time (Kazak, 2001; Stuber, Shemesh, & Saxe, 2003).

This research seems to suggest that a model of posttraumatic stress accurately portrays families facing significant life events by describing those coping well with the event and those

having significant difficulties. While preliminary research in pediatric oncology and injury suggests that a model of traumatic stress is appropriate, researchers are still faced with the task of determining if the model is also suitable for other pediatric populations. While researchers have compared the traumatic stress of these families to families of healthy children, few researchers have compared traumatic stress across disease groups. If this model is appropriate, it should adequately describe the functioning of families facing varying pediatric chronic illnesses. This question led directly to the primary aim of the current study: to directly compare traumatic stress symptoms across three different pediatric chronic illnesses, transplant, Human Immunodeficiency Virus (HIV), and sickle cell disease.

Traumatic Stress across Pediatric Chronic Illness

Preliminary research suggests that children undergoing transplantation and those diagnosed with HIV and sickle cell disease each face significant psychosocial difficulties as they progress from diagnosis to treatment. These difficulties are not only restricted to the youth themselves but may also impact their families. Both youth and their families face numerous challenges as they cope with a complicated chronic illness and, often, uncertain prognosis.

Pediatric Transplant

Recent advances in medicine have dramatically increased the survival rates of children and adolescents receiving solid organ and bone marrow transplants. Once considered experimental, treatment improvements in surgical procedures and post-operative care, especially in immunosuppressant pharmacotherapy (Tredger, Brown, & Dhawan, 2006), have transformed the outlook for youth receiving transplants and their families. Almost 2,000 youth received solid organ transplants in 2005 (2006 OPTN/SRTR Annual Report: Transplant Data 1996-2005, 2006) and over 2000 bone marrow transplants are completed each year (Phipps, 2002). Although three-year survival rates across solid organ transplants, including heart (74-79%), liver (76-80%),

and kidney (95-97%) (2006 OPTN/SRTR Annual Report), and five-year survival rates across bone marrow transplant (47-75%, dependent on donor) are promising (Balduzzi et al., 1995), these prognostic improvements come with considerable psychological cost to both the youth receiving the transplants and their families. Life-threat, invasive medical procedures, complex treatment regimens, and living with a chronic illness all combine to create a stressful environment that puts both the youth and their families at risk for significant psychological difficulties (Engle, 2001).

Recent research examining the psychosocial functioning of transplant candidates and their parents has begun to document the significant impact of the transplant process on the psychosocial functioning of transplant candidates and their families. For example, a recent review of youth undergoing lung transplants found that youth experienced significant psychological distress including depression, anxiety, fear, and behavior problems (Brosig, 2003). In addition, researchers found that youth undergoing heart transplants experienced adjustment difficulties, behavior problems, depression, and anxiety (Todaro, Fennel, Sears, Rodrique, & Roche, 2000) while youth following liver transplantation exhibited significant behavior problems and poor quality of life (Taylor, Franck, Gibson, & Dhawan, 2005b). Interestingly, while those children receiving liver transplants reported that their quality of life improved from pre- to post-transplant, the researchers also found that their quality of life was similar to that of other pediatric chronic illness populations (Taylor, Franck, Gibson, & Dhawan, 2005a). It may be that, for families facing a pediatric chronic illness, it is coping with a chronic illness in general, rather than a specific disease and treatment course, which impacts a child's psychosocial functioning.

Not surprisingly, researchers find similar effects on the psychosocial functioning of parents of children undergoing transplant as well as the family as a whole. For example, researchers found that family functioning is significantly related to child psychosocial functioning in pediatric heart transplant (DeMaso, Twente, Spratt, & O'Brien, 1995) and pediatric bone marrow transplant (DeMaso, Kelley, Bastardi, O'Brien, & Blume, 2004) populations. Although few studies examine the contribution of family functioning in relation to parent outcome variables, researchers have found that pediatric transplant negatively impacts the psychosocial functioning of parents. Similar to studies of child psychosocial functioning, researchers found that parents also report significant psychological distress, both before and after their child undergoes a transplant (Phipps, Dunavant, Lensing, & Rai, 2005). Researchers found that mothers of children undergoing either solid organ or bone marrow transplants experienced significant parenting, financial, care-giving, and family stress (Rodrique et al., 1997) while fathers reported significant financial stress, but less parenting and family stress, than parents of healthy children (Rodrique et al., 1996). Although variation exists, the majority of research suggests that parents of youth undergoing both solid organ and bone marrow transplants face significant psychological difficulties both before and after transplantation.

Given these significant difficulties, it is even more interesting that both children and their parents report significant traumatic stress symptoms. Researchers found that in a sample of 18 youth receiving liver transplants, youth reported significant posttraumatic stress symptoms (Walker, Harris, Baker, Kelly, & Houghton, 1999) while in another sample of 19 youth receiving liver transplants, over 30% of youth reported high scores on a measure of posttraumatic symptomatology (Shemesh et al., 2000). Researchers have also documented that parents experience significant posttraumatic symptoms during the transplant process (Manne et al., 2004;

Young et al., 2003). In a study of parents of children three months to ten years following heart transplant, approximately 40% of parents reported some traumatic stress symptoms and over 20% of parents met clinical criteria for a diagnosis of PTSD (Farley et al., 2007). It seems that both children undergoing a transplant and their parents report significant traumatic stress symptoms; however, if these symptoms are unique to the pediatric transplant population in particular or are associated with coping with a pediatric chronic illness in general is less clear.

Pediatric HIV

Similar to the pediatric transplantation literature, medical advances in pediatric HIV have also dramatically improved the prognosis for children and adolescents living with the virus. Recent data suggest that approximately 2.3 million youth under 15 years of age are currently living with HIV (World Health Organization, 2005). In the United States alone, approximately 46,000 youth under 13 years of age are living with HIV or acquired immunodeficiency syndrome (AIDS; Centers for Disease Control and Prevention, 2005). Given these numbers, it is not surprising that medical researchers have expended a great deal of energy in finding new, more successful methods to treat these individuals and prolong their life expectancy. Although there is still no cure for HIV/AIDS, the advent of antiretroviral medications and combination-drug treatment approaches (Dixon & Cunningham, 2007; Yeni et al., 2002) have dramatically increased the survival rates of children and adolescents diagnosed with HIV. For example, compared to 2001, an additional 27% of individuals in the United States were living with AIDS in 2005 due to improvements in antiretroviral treatment (Centers for Disease Control and Prevention). This number is in comparison to the only seven percent increase in new diagnoses. While promising, these intensive treatments also come with considerable cost to the individual and their family. Access to treatment (Dunne, 2007), complex treatment regimens (Ikeda Ch'ng, Oleske, 2007), and continued life threat each contribute to significant psychological difficulties

for youth and their families while they cope with HIV (Steele, Nelson, & Cole, 2007; Sherwen & Boland, 1994).

The psychosocial functioning of children whose parents have been diagnosed with HIV (Lee & Rotheram-Borus, 2002; Rotheram-Borus et al., 2003; Rotheram-Borus, Lee, Lin, & Lester, 2004) and the appropriate disclosure of HIV status to children (Wiener, Mellins, Marhefka, & Battles, 2007; Gerson et al., 2001) has been well studied. Unfortunately, there is less research currently available examining the psychosocial functioning of children and adolescents who are diagnosed with HIV/AIDS and no consensus regarding the impact of the diagnosis is available. For example, researchers comparing the psychosocial functioning of school-age children on measures of depression, anxiety, and self-concept did not find that children diagnosed with HIV reported significantly more symptoms than their healthy peers (Bachanas et al., 2001). Other researchers, however, have found that children diagnosed with HIV display significant psychosocial difficulties. Bose and colleagues (Bose, Moss, Brouwers, Pizzo, & Lorion, 1994) found that parents of school-aged children with HIV reported that their children displayed significant anxiety, conduct problems, and social difficulties while Byrne and Honig (2006) found that parents reported significantly lower scores on measures of general health and physical functioning while describing their children's quality of life. Studies such as these, examining the psychosocial functioning of children with HIV/AIDS, are increasingly important, not only in themselves, but also because psychosocial difficulties in this population are often related to risky sexual behaviors, alcohol use and substance use (Murphy et al., 2001).

As one might expect, the psychosocial functioning of parents and families is also impacted when a child or adolescent is initially diagnosed with HIV/AIDS. For example, in a study by Wiener and colleagues (Wiener, Vasquez, & Battles, 2001), approximately 50% of

fathers of HIV infected children reported significant parenting stress and distress. In addition, parents of children diagnosed with HIV reported more often using passive coping styles (Martin, Wolters, Klaas, Perez, & Wood, 2004) and social distance (Hardy, Routh, Armstrong, Albrecht, & Davis, 1995) while parenting. The psychosocial functioning of parents and the overall family is significant in that it is often related to outcomes for their children. Compared to parents of adherent children, parents of non-adherent youth reported difficulties in communication, higher stress and lower quality of life (Mellins, Brackis-Cott, Doleza, & Abrams, 2004). It seems obvious that the psychosocial functioning of both children and parents is related to one another and that the functioning of parents significantly impacts children's later health outcomes. Unfortunately, compared to the pediatric transplant literature, the use of a model of traumatic stress to understand the impact of disease on psychosocial functioning has been applied even less.

In fact, only one study is currently available that describes traumatic stress symptoms in youth with HIV/AIDS. In a study of 30 young adults and adolescents with HIV/AIDS, researchers found that approximately 13% of participants reported symptoms suggestive of a diagnosis of PTSD while an additional 20% of participants reported significant traumatic stress symptoms following their diagnosis (Radcliffe et al., 2007). Despite only a single study in the pediatric population, the use of PTSD as a model of psychosocial adjustment has often been successfully applied to the adult HIV/AIDS population. Across a number of studies, researchers have found that adults infected with HIV/AIDS report significant traumatic stress symptoms related to their diagnosis (Katz & Nevid, 2005; Leserman et al., 2005; Olley, Zeier, Seedat, & Stein, 2005). Although these studies begin to suggest that individuals infected with HIV/AIDS experience significant traumatic stress symptoms, no studies are currently available examining

the parents of youth infected with HIV/AIDS or comparing rates of traumatic stress symptoms to other chronic illness populations.

Pediatric Sickle Cell Disease

Not surprisingly, recent medical advances have also dramatically improved the lives of children and adolescents diagnosed with sickle cell disease. Characterized by a genetic defect in hemoglobin production, sickle cell disease affects approximately 50,000 African Americans in the United States alone. Infection, anemia, stroke, gallbladder disease, renal disease, and pain are among only some of the complications that children and adolescents with sickle cell disease may experience (Wethers, 2000). Similar to HIV/AIDS, there is no cure for sickle cell disease; however, there are many promising advances in medications that help to alleviate the various symptoms of the disorder (Adams-Graves et al., 1997). Unfortunately, both the complications and treatments associated with the disease do not come without a psychosocial cost to both the child and their parent.

Although there is considerable variation in regard to the impact of sickle cell disease on children's psychosocial functioning, many researchers have documented the detrimental effects associated with the disease. Compared to their siblings, younger children with sickle cell disease are more likely to exhibit externalizing problems while older children are more likely to exhibit internalizing symptoms (Brown et al., 1993). Peers of school age children with sickle cell disease are more likely to describe these youth as having fewer friends and being less athletic (Noll, Reiter-Purtill, Vannatta, Gerhardt, & Short, 2007). As expected, these psychosocial difficulties are also often associated with overall adaptation. For example, in a multi-site study of African American adolescents with sickle cell disease, self-esteem, assertiveness, and social support were all related to teenagers' overall adaptation (Burlew, Telfair, Colangelo, & Wright, 2000).

Parent and family psychosocial functioning are also related to youth's ability to adaptively cope with their illness. Both caregiver and child social adjustment (Brown, Connelly, Rittle, & Clouse, 2006), parental stress (Logan, Radcliffe, & Smith-Whitley, 2002), and family functioning (Mitchell et al., 2007) are related to children's health care utilization over time. Often, parental coping is related to children's coping (Brown et al., 1993) while adapting to living with sickle cell disease. Indeed, the functioning of the family is also often related to children's psychosocial functioning (Kell, Kliewer, Erickson, & Ohene-Frempong, 1998; Thomson et al., 2003).

Given this relationship between parent and child psychosocial functioning, it is not surprising that researchers have begun to examine posttraumatic stress in the pediatric sickle cell population. However, similar to studies of traumatic stress in pediatric transplantation and pediatric HIV, the research is this area is still relatively new. In fact, only one study is currently available that documents traumatic stress in this population. In a sample of 11 children with sickle cell disease who had experienced at least one hospitalization related to their disease, almost 30% of youth and 40% of parents reported symptoms consistent with a diagnosis of PTSD (Hofmann, Montalembert, Beauquier-Maccotta, de Villartay & Golse, 2007). Although only one study of this nature has currently been published, it provides promising evidence that traumatic stress may be an appropriate model to describe the psychosocial functioning of both youth living with sickle cell disease and their parents.

Differences in Traumatic Stress Symptoms across Illness Groups

While studies across pediatric transplant (Manne et al., 2004; Young et al. 2003; Shemesh et al., 2000; Walker et al., 1999), pediatric HIV (Radcliffe et al., 2007), and pediatric sickle cell disease (Hofmann et al., 2007) populations each document significant difficulties that youth and their families face, it is difficult to gain any clear understanding of how these

populations are doing as a whole. Research that documents that these populations each experience traumatic stress symptoms suggests that this model may describe all three disease groups; however, exactly how traumatic stress varies across these groups remains uncertain. Indeed, some research suggests that particular pediatric chronic illness populations may face more traumatic stress symptoms than do other groups. For example, researchers studying a sample of youth receiving liver transplants found that these youth reported more traumatic stress symptoms than children undergoing routine surgery or youth with other chronic illnesses (Walker et al., 1999). In contrast, in a study of parents of youth undergoing solid organ transplants, parent-reported rates of traumatic stress were similar to those previously reported in a sample of parents of children with cancer (Young et al., 2003).

Despite these mixed findings in regard to possible differences in traumatic stress symptoms, previous research demonstrating that life threat (Hobbie et al., 2000) is associated with greater posttraumatic stress symptoms in cancer also suggests that significant differences in symptoms across pediatric chronic illness populations may exist. Compared to pediatric HIV (Dixon & Cunningham, 2007; Yeni et al., 2002) and pediatric sickle cell disease (Adams-Graves et al, 1997) where life expectancy has been greatly extended by improved treatment regimens, children and families entering the pre-transplantation process are facing more acute life threat (Engle, 2001). This difference provides tempting evidence suggesting possible differences in traumatic stress symptoms across pediatric chronic illness groups such that children and families prior to transplantation will report greater traumatic stress symptoms than children diagnosed with sickle cell disease and children diagnosed with HIV.

Unfortunately, many of the studies described above, while documenting important psychosocial challenges that youth and parents face, make it difficult to draw conclusions across

different pediatric chronic illness populations. In addition, it is difficult to account for individual differences in adjustment within the previous body of literature. Although it is certain that some children and their parents report significant traumatic stress symptoms, other individuals seem to adjust well to their chronic condition. This difference, those coping well and those coping poorly, cannot be accounted for by the various different methodologies described above. Their methodology (i.e., examining individual chronic illness groups), while helping to control for variance, makes it difficult to generalize from one population to another or to draw conclusions about the pediatric population in general. In addition, most studies examine only a small number of psychological variables and use widely different measurement techniques (e.g., interview versus questionnaire; child versus parent report) making it difficult to create a single coherent picture of the psychological difficulties these youth and parents face.

Differences between Parent and Child Report of Traumatic Stress

The use of either child self-report or parent-proxy-report of traumatic stress is one possible variable contributing to the significant differences in regard to reported rates of traumatic stress symptoms across pediatric chronic illness populations. Integral to creating a coherent picture of the difficulties youth and their parents face is obtaining the most accurate information regarding youth's psychosocial functioning. Many researchers have debated the advantages and disadvantages of youth self-report compared to parent-proxy-reports of youth's psychological functioning (Eiser & Morse, 2001). For example, advocates of parent-proxy-report measures question children's understanding of their disease, time perception, and cognitive development (Connolly & Johnson, 1999) while advocates of child self-report measures cite evidence that even young children can rate their own quality of life and can provide reliable interpretations of events, even though these interpretations may be different than those of adults (Eiser, Mohay, & Morse, 2000). Although this debate continues, researchers

from both sides agree that gaining the most accurate information regarding youth's functioning is imperative to evaluating interventions, dispensing resources, and making medical treatment decisions (Eiser & Morse, 2001).

Researchers studying other chronic illness populations such as obesity (Williams, Wake, Hesketh, Maher, & Waters, 2005), cancer, (Russell, Hudson, Long, & Phipps, 2006), and diabetes (Hesketh, Wake, & Cameron, 2004) have documented varying results regarding differences between parent-proxy-report and youth self-report of psychological functioning. For example, Phipps and colleagues (Phipps, Long, Hudson, & Rai, 2005) did not find significant differences in parent-proxy-report and child self-report of traumatic stress symptoms in a sample of children diagnosed with cancer. In comparison, researchers studying children following injury found that approximately twice the numbers of traumatic stress symptoms were reported when using both parent-proxy and child self-report measures compared to using parent-proxy report alone (Scheeringa, Wright, Hunt, & Zeanah, 2006). In addition, other researchers studying the pediatric injury population have reported that, while children and parents report similar symptoms of traumatic stress over time, children report significantly more symptoms of traumatic stress immediately following the injury than do their parents (Schreier et al., 2005).

Although few studies are available, researchers in the pediatric transplant population have previously reported differing results with regard to parent versus child report of traumatic stress For example, researchers examined differences in reports of both depressive and posttraumatic stress symptoms between 30 youth receiving solid organ transplants (liver, heart, kidney), their parents, and clinicians compared to other chronically ill children (Shemesh, Annunziato, et al., 2005). They found that parents of children receiving transplants were less likely to report that their children experienced depressive or posttraumatic symptoms than parents of other

chronically ill children. In contrast, children receiving transplants were as likely to report depressive and posttraumatic symptoms as other chronically ill children (Shemesh, Annunziato et al.). While no studies are available examining differences in parent-proxy and child self-report of traumatic stress in pediatric sickle cell or HIV, researchers have examined differences in quality of life between parents and children coping with sickle cell disease such that parents reported significantly worse overall quality of life than did their children (Panepinto, O'Mahar, DeBaun, Loberiza, & Scott, 2005).

In contrast, other studies examining child and parent-proxy reports of child functioning have not documented significant differences. For example, researchers examining the functioning of youth stem cell recipients found that, while significant differences between parents and children on some dimensions of quality of life (e.g., physical functioning), parents and children tended to agree on their reports of the child's overall quality of life (Nuss and Wilson, 2007). While some studies are suggestive of significant differences between child and parent-proxy report (e.g., depressive, posttraumatic symptomatology) other researchers have not documented significant differences (e.g., quality of life). However, the small number of constructs measured and the populations recruited limit the conclusions drawn. In addition, the studies examined specific, but different, constructs and used different measures, making it difficult to draw any conclusions about overall differences in this population.

Predictors of Traumatic Stress

Perhaps one of the most promising explanations for possible differences in parent-proxy and child self-report of traumatic stress symptoms is the traumatic stress symptoms experienced by parents themselves. Indeed, it is important to examine possible predictors (e.g., parental traumatic stress) of child traumatic stress symptoms to help better understand the psychological functioning of children and the accuracy of a model of traumatic stress in describing their

symptoms. For example, Schreier and colleagues (Schreier et al., 2005) found that children's traumatic stress symptoms were significantly related to parents' own traumatic stress symptoms in a sample of children following injury. Shemesh and colleagues (Shemesh, Newcorn, et al., 2005) also found a similar relationship between parent and child symptoms of traumatic stress. Examining children being followed in specialty medical clinic, the researchers found that parents' traumatic stress symptoms were significantly related to their report of their children's symptoms. Although this research suggests a significant relationship between parental and child traumatic stress symptoms, few other studies are currently available that examine this relationship and, to date, no studies are available that examine this relationship across pediatric transplant, sickle cell disease, or HIV groups.

In addition to parental traumatic stress symptoms, the functional status or disease severity of children has also been hypothesized as an important predictor of traumatic stress symptoms in children. For example, in a study across pediatric cancer, diabetes, and injury populations, researchers found that children's functional status significantly predicted traumatic stress symptoms by both children's self-report and parents' proxy-report (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003). Similarly, Hobbie and colleagues (Hobbie et al., 2000) found higher perceived current life threat and more intense treatment histories in young adult survivors of cancer while Holbrook and colleagues (Holbrook et al., 2005) found perceived current life threat predicted traumatic stress symptoms in children following trauma requiring hospitalization.

Although these are only two possible predictors of children's traumatic stress symptoms, research in this area remains extremely limited and has rarely been applied to other pediatric chronic illness populations. If traumatic stress is an adequate model to describe the

psychological functioning of children and families, then determining possible predictors of chronically ill children's traumatic stress symptoms has important implications for later intervention in this population.

Overview of Current Literature

Taken together, previous findings in the area of traumatic stress suggest that chronically ill youth and their families experience considerable psychological difficulties; however, significant differences among individual studies exist. Most previous studies assessed only a small number of variables, examined only one chronic illness population, or did not examine both children and their families. In addition, few studies sought to understand youth, family, and parent psychosocial functioning under the umbrella of one general psychological model. While studies from individual populations suggest that posttraumatic stress may be an informative model from which to understand pediatric chronic illness, few studies have explored possible predictors of posttraumatic stress or directly compared traumatic stress symptoms across groups. In addition, the wide variability in study design has made it difficult to draw definitive conclusions regarding functioning across different chronic illness groups. Lastly, the majority of previous studies were descriptive in nature, comparing the psychological functioning of transplant candidates and their families to other populations; few studies examined possible predictors of psychological distress. Such examination has important implications for later treatment and intervention.

Given the serious consequences of youth and family psychological functioning, the current study sought to examine both youth and parent posttraumatic stress symptoms in pediatric transplant candidates, youth diagnosed with sickle cell disease, and youth living with HIV. Building on previous research, the current study attempted to provide a description of the psychological functioning of both chronically ill youth and their parents using a theoretical

framework of posttraumatic stress and to directly compare traumatic stress symptoms across all three chronic illness groups. Specific aims and hypotheses of the current study are described below.

Current Study Aims and Hypotheses

Primary Aims

Aim 1: To examine traumatic stress symptoms across disease groups

Hypothesis 1.1. The researchers hypothesized that transplant candidates would report greater traumatic stress symptoms than participants diagnosed with pediatric sickle cell disease and HIV by both child self-report and parent-proxy-report of traumatic stress symptoms.

Hypothesis 1.2. The researchers hypothesized that parents of transplant candidates would report greater traumatic stress symptoms than the parents of participants diagnosed with pediatric sickle cell disease and HIV.

Aim 2: To compare parent-proxy-report and youth self-report of traumatic stress symptoms

Hypothesis 2.1. The researchers hypothesized that children across chronic illness groups would report significantly greater traumatic stress symptoms by self-report than their parents by parent-proxy-report.

Aim 3: To determine possible predictors of children's posttraumatic stress symptoms

Hypothesis 3.1. The researchers hypothesized that parent traumatic stress symptoms and child functional status would predict children's traumatic stress by child self-report.

Hypothesis 3.2. The researchers hypothesized that parent traumatic stress symptoms and child functional status would predict children's traumatic stress by parent-proxy-report.

Secondary Aims

In addition, the current studied explored in greater depth the quality of life and family functioning of pediatric pre-transplant candidates.

Aim 4: To examine the quality of life of pre-transplant candidates

Hypothesis 4.1. The researchers hypothesized that children would report lower quality of life compared to previously published quality of life data in the healthy and chronic illness pediatric populations.

Hypothesis 4.2. The researchers hypothesized that parents would describe their children's quality of life as lower than previously published quality of life data in the healthy and chronic illness pediatric populations.

Aim 5: To examine the family functioning of pre-transplant candidates' families

Hypothesis 5.1. The researchers hypothesized that a greater percentage of families of pre-transplant candidates would fall in the unhealthy range of family functioning compared to previously published data in the healthy and chronic illness pediatric populations.

CHAPTER 2
METHOD

Participants

The current study included a total of 67 youth (51% female) aged 2 to 17 years (*M* = 11.18, *SD* = 4.78) and their parents or legal guardians aged 20 to 70 years (*M* =40.16, *SD* = 11.75). Youth included 26 pediatric transplant candidates comprising youth under consideration for solid organ (heart, lung, heart/lung, liver, and kidney) and bone marrow transplants, 13 youth diagnosed with and aware of their diagnosis of HIV, and 28 youth with sickle cell disease and their parents. Across disease groups, children were diagnosed with their current condition 0 months to 17.9 years prior to their date of participation in the current study (*M* = 89.35 months, *SD* = 67.26). Demographic characteristics of child participants by disease group are summarized in Table 2-1. Parents included primarily mothers (71.2% mothers, 10.2% fathers, 8.5% grandparents, and 10.2% other legal guardians) who were married (44.1% married, 28.8% single, 18.6% divorced, and 8.5% other) and reported a median family income of 20,000-29,999 dollars per year. Demographic characteristics of parent participants by disease group are summarized in Table 2-2. Inclusion criteria across chronic illness groups required that the participating youth (1) had a previously scheduled outpatient appointment at one of three specialty outpatient clinics and (2) that a parent or other legal guardian was present at the time of the scheduled appointment. A diagnosis of mental retardation or psychotic disorder excluded potential participants from the study.

Procedures

Youth were recruited from three separate outpatient clinics. Procedures for recruitment in each chronic illness population are summarized below. The local institutional review board approved all procedures.

Pediatric Transplant

Participants were youth referred for an outpatient, pre-transplant psychological evaluation at the University of Florida Psychology Clinic and their parents. Families completed a battery of measures as part of their routine psychological evaluation prior to their scheduled appointment. A research team member approached potential participants prior to this scheduled appointment to describe the study and to obtain consent to use completed measures that were included as part of their routine evaluation for the current study.

Pediatric Sickle Cell Disease

Participants were youth with a scheduled, outpatient appointment at the University of Florida sickle cell disease clinic and their parents or legal guardians who were approached by a member of the medical team to determine if they were interested in learning about a research study. If interested, a trained research team member approached potential participants in their exam room to describe the current study and to obtain consent. Participants completed all measures while they were waiting for their physician appointment and returned the measures to the research team member before leaving the clinic.

Pediatric HIV

Participants were youth with a scheduled, outpatient appointment at the University of Florida HIV clinic and their parents or legal guardians. A member of the medical staff first verified the youth's knowledge of their current diagnosis from the child's parent or legal guardian. After confirming that youth were informed of their diagnosis of HIV, families were approached by a member of the medical team in their exam room to determine if they were interested in learning about a research study. If interested, participants completed measures while they were waiting for the physician and returned the measures to the research team member before leaving the clinic.

Measures

Participants completed the following measures described below. Table 2-3 describes the measures completed by parents and children by disease group. As described in the table, not all participants completed all measures. Participants completed selected measures prior to their scheduled outpatient pre-transplant psychological evaluation or during their scheduled appointment in a specialty medical clinic.

Parent Completed Measures

Demographic questionnaire

Parents or legal guardians completed a questionnaire covering general demographic information for the youth and family and the youth's medical history. This questionnaire asked for information regarding the child's medical diagnosis, previous treatment and hospitalizations, and current treatment regimen. These questionnaires were modified slightly in regards to disease specific information for each of the three chronic illness groups.

Impact of events scale – revised

The participating youth's parent or legal guardian completed the Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997), a 22-item self-report measure that assesses current life distress. The measure includes three subscales: avoidance, intrusions, and hyperarousal scales. The measure also includes a general composite IES-R total score where a higher score indicates more posttraumatic symptoms. Previous researchers recommend a total score of 30 or higher as suggestive of a diagnosis of PTSD. Previous studies also support the use of the overall score in individuals with lower symptom levels (i.e., as a measure of posttraumatic stress symptoms even in individuals who have a score lower than 30; Creamer, Bell, & Failla, 2003). The measure has demonstrated good reliability and validity in adult populations (Weiss & Marmar). Researchers used this measure in studies measuring posttraumatic symptoms of parents of chronically ill

youth (Shemesh, Newcorn, et al., 2005) and parents of youth with cancer (Kazak, Alderfer, Rourke, et al., 2004).

Functional disability inventory

Parents across all three chronic illness groups completed the Functional Disability Inventory (FDI; Walker & Greene, 1991). The FDI is a 15-item measure of children's general physical functioning. Parents rated their child on various physical activities over the past two weeks on a four-point likert scale from 0 (no trouble) to 4 (impossible). Items were summed to calculate a total score where higher scores indicate greater functional disability. The measure has been used to measure physical disability in children with chronic pain syndromes (Logan & Scharff, 2005) and children with emotional difficulties (Garralda & Rangel, 2004). Previous research has provided support for its reliability and validity in measuring physical disability in pediatric populations (Walker & Greene).

Family assessment device

Parents of pre-transplant candidates completed the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983), a general measure of family functioning. The 60-item measure includes six subscales: problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control. An overall score, the general functioning scale, can also be calculated. Individuals rated each item on a four-point likert scale from 1 (strongly agree) to 4 (strongly disagree). Higher scores on this measure indicate more maladaptive family functioning. Previous researchers found support for the validity and reliability of the measure's general functioning scale (Ridenour, Daley, & Reich, 1999) while other researchers have used this measure to study the family functioning of chronically ill children (Bihun, Wamboldt, Gavin, & Wamboldt, 2002; Fiese & Wamboldt, 2003).

Parent and Youth Completed Measures

UCLA posttraumatic stress disorder reaction index

Youth and parents each completed age-appropriate versions of the UCLA Posttraumatic Stress Disorder Reaction Index (PTSRI; Rodriguez, Steinberg, & Pynoos, 1998), a measure of posttraumatic stress symptoms in youth used across a variety of chronic illness populations (Steinberg, Brymer, Decker, & Pynoos, 2004). The entire measure includes three components. The third component, which includes a 17-item likert scale that corresponds to DSM-IV-TR symptom criteria for PTSD, was used for all analyses. The measure includes three versions: a child version (eight to 12 years), an adolescent version (above 12 years), and a parent-proxy counterpart where higher scores indicate greater traumatic stress symptoms. The authors recommend a total score 38 or higher on the third component as suggestive of PTSD. Other researchers previously used the third component of this measure to assess posttraumatic symptoms in chronically ill children (Shemesh, Annunziato, et al., 2005), children undergoing liver transplants (Shemesh et al., 2000), and adolescents undergoing liver, heart or kidney transplants (Mintzer et al., 2005).

Pediatric quality of life inventory

Pre-transplant candidates and their parents each completed age-appropriate versions of the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Kurtin, 2001), a well established generic instrument assessing physical and psychosocial dimensions of youth quality of life. The PedsQL includes four versions: a child form (ages eight to 12), an adolescent form (ages 13 to 18), a parent-proxy form for children (ages eight to 12), and a parent-proxy form for adolescents (ages 13 to 18). The 23-item measure includes four individual subscales (physical, emotional, social, and school) and three summary scores: a psychosocial health summary score, a physical health summary score and a total scale score. Individuals rated on a five-point likert scale “how

much of a problem" certain items have been for the child or adolescent over the past month. Higher scores on this measure indicate better quality of life. These scores have demonstrated good reliability and validity in a variety of pediatric populations and researchers have found factor-analytic support for the conceptually derived scales (Varni, Burwinkle, Jacobs, et al., 2003; Varni, Burwinkle, Seid, & Skarr, 2003; Varni et al., 2001).

Table 2-1. Demographic characteristics of child participants

	Transplant			HIV			Sickle Cell Disease		
	M	*SD*	%	*M*	*SD*	%	*M*	*SD*	%
Child age	11.33	4.64		13.15	2.41		10.14	5.48	
Child gender									
Female			40			54.5			58.3
Male			60			45.5			41.7
Child race									
Caucasian			47.6			15.4			0
African American			38.1			46.2			100
Hispanic			14.3			15.4			0
Other			0			23.1			0
Child minority status*									
Minority			47.6			15.4			0
Non-minority (Caucasian)			52.4			84.6			100
Longest hospitalization (days)*	45.59	53.85		13.14	21.08		9.00	12.61	
Time since diagnosis (months)	56.21	68.31		125.33	58.96		97.59	61.12	

* $p < .01$

Table 2-2. Demographic characteristics of parent participants

	Transplant			HIV			Sickle Cell Disease		
	M	*SD*	%	*M*	*SD*	%	*M*	*SD*	%
Parent age*	36.11	7.24		52.28	6.33		36.85	12.38	
Parent race									
Caucasian			52.6			46.2			0
African American			31.6			30.8			100
Hispanic			10.5			15.4			0
Other			5.3			7.7			0
Parent relationship to child									
Mother			87.0			30.8			78.3
Father			8.7			23.1			4.3
Grandparent			0			23.1			8.7
Other legal guardian			4.3			23.1			8.6
Parent marital status									
Married			63.2			38.5			33.3
Single			21.1			15.4			40.7
Divorced			15.8			23.1			18.5
Other			0			23.1			7.4
Family income									
≤ $9,999			11.8			23.1			27.2
$10,000 - $19,999			23.5			7.7			22.7
$20,000 - $39,999			29.4			31.0			36.3
$40,000 - $59,999			11.8			0			9.1
$60,000 - $79,999			17.7			30.8			0
≥ $80,000			5.9			7.7			0

* $p < .01$

Table 2-3. Measures completed by participants by disease group

	Pre-Transplant	HIV	Sickle Cell Disease
Clinic:	Psychology Clinic	Pediatric HIV Clinic	Pediatric SCD Clinic
Parent measures:	Demographic form FDI IES-R Parent-proxy PTSRI Parent-proxy PedsQL FAD	Demographic form FDI IES-R Parent-proxy PTSRI	Demographic form FDI IES-R Parent-proxy PTSRI
Child measures (ages 8-17):	Self-report PTSRI Self-report PedsQL	Self-report PTSRI	Self-report PTSRI

CHAPTER 3
RESULTS

Statistical Analyses

Unless otherwise stated, SPSS for Windows (SPSS Inc., 2007) was used for all analyses. Correlational and descriptive analyses were completed amongst variables of interest and demographic variables. Ethnicity was recoded as a dichotomous variable: minority (African American, Hispanic, Native American, other) or non-minority (Caucasian). Given their negatively skewed distributions, child functional status total score and parent and child traumatic stress symptom total scores were log transformed to approximate a normal distribution for subsequent ANCOVA and regression analyses.

Aim 1: To Examine Traumatic Stress Symptoms across Disease Groups

Analyses for the first aim included descriptive statistics to determine the percentage of youth and parents who met clinical cut-off for traumatic stress symptoms that are suggestive of a diagnosis of PTSD. Analysis of Covariance (ANCOVA) models were completed to assess possible differences in traumatic stress symptoms across groups. Separate ANCOVA equations compared traumatic stress symptoms (1) across youth being considered for transplant, youth diagnosed with HIV, and youth diagnosed with sickle cell disease by child self-report, (2) across youth by parent-proxy-report and (3) across parents from the three child illness groups based on parent self-report. Demographic variables that differed significantly between groups (i.e., parent age, length of longest hospitalization, and child minority status) were entered as covariates into each of the separate ANCOVA models. If appropriate, post hoc analyses were also conducted to further examine significant main effects by group.

Aim 2: To Compare Parent-Proxy-Report and Youth Self-Report of Traumatic Stress Symptoms

Paired-samples t-tests were conducted to compare child self-report and parent-proxy-reports of children's traumatic stress symptoms.

Aim 3: To Determine Possible Predictors of Children's Posttraumatic Stress Symptoms

Similar to the method outlined by Young and colleagues (2003), hierarchical regression analysis was used to determine predictors of youth posttraumatic stress symptoms. Four separate regression equations were completed. Related demographic variables, including parent age, child minority status, and length of longest hospitalization were included in the first block of each regression equation. The predictor variable, either child physical status (FDI total score) or parent self-reported traumatic stress symptoms (IES-R total score), was entered into the second block of the regression equation. Dependent variables included youth self-reported traumatic stress symptoms (Child PTSRI total score) or parent-proxy-reported traumatic stress (Parent PTSRI total score). Exploratory analyses were also conducted to examine possible predictors of parent self-reported traumatic stress symptoms.

Aims 4 and 5: To Examine the Quality of Life and Family Functioning of Pre-Transplant Candidates

The researchers conducted descriptive statistics to determine the quality of life (Aim 4) and family functioning (Aim 5) of pediatric transplant candidates. Independent samples t-tests were performed using NCSS and PASS statistical software (Hintze, 2004) to determine possible differences in the quality of life and family functioning of pre-transplant candidates compared to previously published data for healthy and chronically ill children.

Preliminary Analyses

As shown in Tables 2-1 and 2-2, preliminary ANOVA analyses revealed significant differences between disease groups across the following variables: parent age ($p < .01$), child

minority status ($p < .01$), and child's longest hospitalization in days ($p < .01$). Descriptive statistics for child functional status (FDI total), parent self-reported traumatic stress symptoms (IES-R total), parent-proxy-reported traumatic stress symptoms (Parent PTSRI total), and child self-reported traumatic stress symptoms (Child PTSRI total) are shown in Table 3-1.

Table 3-2 shows a correlation matrix examining the associations between child gender (male, female), child age, child race (minority, non-minority), FDI total score, IES-R total score, parent PSTRI total score, and child PSTRI total score. As shown, child age was significantly correlated with the parent PRSRI total score such that parents reported greater symptoms for older children ($r = .27$, $p < .05$). IES-R total score was significantly correlated with the parent PTSRI total score such that parents who reported they were experiencing great traumatic stress symptoms also reported their children were experiencing greater symptoms by parent-proxy-report ($r = .27$, $p < .05$). Lastly, child self-reported traumatic stress symptoms and parent proxy-reported traumatic stress symptoms were also significantly correlated with one another ($r = .52$, $p < .01$) such that parent-proxy-reported and child self-reported child traumatic stress symptoms were positively related.

Reliability for each of the primary measures was calculated using the Cronbach's alpha statistic. Reliability was good across all the measures: child PTSRI ($\alpha = .92$), parent-proxy PTSRI ($\alpha = .94$), parent IES-R ($\alpha = .96$), and the FDI ($\alpha = .95$).

Primary Aims

Aim 1: To Examine Traumatic Stress Symptoms across Disease Groups

Youth self-reported traumatic stress

As shown in Table 3-3, 10% of youth reported rates of traumatic stress symptoms suggestive of a diagnosis of PTSD by self-report. Across disease groups, 15.4% of pre-transplant candidates, 8.3% of children diagnosed with HIV, and 6.7% of children diagnosed with sickle

cell disease reported symptoms of traumatic stress suggestive of a clinical diagnosis of PTSD by self-report. Of note, fewer children (n = 45) across disease groups completed the traumatic stress measure than parents due to child age (i.e., only children aged eight and above completed self-report measures).

Symptom level means used in the ANCOVA model are shown in Table 3-1. Analysis of the ANCOVA model examining differences in *child self-reported traumatic stress* symptoms indicated a significant main effect of group in child-reported traumatic stress symptoms (F [2,22] = 4.12, p = 0.03, η^2 = 0.27). The main effect of group was explored using post-hoc paired samples t-tests. Pediatric transplant candidates reported greater traumatic stress symptoms than children diagnosed with HIV (t = 0.57, p = 0.03). All other post-hoc tests were not statistically significant. The model indicated a non-significant main effect of parent age (F [1, 22] = 1.31, p = 0.27, η^2 = 0.06), a non-significant main effect of child minority status (F [1, 22] = 0.07, p = 0.80, η^2 = 0.003), and a significant main effect of length of longest hospitalization (F [1, 22] = 10.09, p = 0.004, η^2 = 0.31).

Parent-proxy-reported traumatic stress

As shown in Table 3-3, 18% of parents reported their children demonstrated rates of traumatic stress symptoms suggestive of a diagnosis of PTSD by parent-proxy-report. Across disease groups, 18.8% of parents of pre-transplant candidates, 15.4% of parents of children diagnosed with HIV, and 19.0% of parents of children diagnosed with sickle cell disease reported that their children demonstrated symptoms of traumatic stress suggestive of a clinical diagnosis of PTSD by parent-proxy-report.

Symptom level means used in the ANCOVA model are shown in Table 3-1. Analysis of the ANCOVA model examining differences in *parent-proxy-reported traumatic stress* symptoms did not indicate a significant main effect of group in parent-proxy-reported traumatic stress

symptoms (F [2,31] = 2.07, p = 0.14, η^2 = 0.12). The model indicated a non-significant main effect of parent age (F [1, 31] = 0.38, p = 0.54, η^2 = 0.01), a non-significant main effect of child minority status (F [1, 31] = 0.23, p = 0.64, η^2 = 0.01), and a non-significant main effect of length of longest hospitalization (F [1, 31] = 2.10, p = 0.16, η^2 = 0.06).

Parent self-reported traumatic stress

As shown in Table 3-3, 12.9% of parents across disease groups reported rates of traumatic stress symptoms suggestive of a diagnosis of PTSD. Across disease groups, 14.3% of parents of pre-transplant candidates, 7.7% of parents of children diagnosed with HIV, and 14.3% of children diagnosed with sickle cell disease reported symptoms of traumatic stress suggestive of a clinical diagnosis of PTSD.

Symptom level means used in the ANCOVA model are shown in Table 3-1. Analysis of the ANCOVA model examining differences in *parent self-reported traumatic stress* symptoms did not indicate a significant main effect of group in parent-self-reported traumatic stress symptoms (F [2,37] = 1.24, p = 0.30, η^2 = 0.06). The model indicated a non-significant main effect of parent age (F [1, 37] = 2.11, p = 0.16, η^2 = 0.05), a non-significant main effect of child minority status (F [1. 37] = 0.27, p = 0.61, η^2 = 0.01), and a non-significant main effect of length of longest hospitalization (F [1, 37] = 0.56, p = 0.46, η^2 = 0.02).

Aim 2: To Compare Parent-Proxy-Report and Youth Self-Report of Traumatic Stress Symptoms

Paired-samples t-tests examining possible differences in child-self-reported and parent proxy-reported traumatic stress symptoms are summarized in Table 3-4. Analyses revealed significant differences between child-self-reported and parent-proxy-reported traumatic stress symptoms (t = 2.39, p = 0.02) across disease groups such that children reported greater symptoms than parents by child self-report. As shown in Table 3-4, both parents and children

reported varying levels of traumatic stress symptoms across disease groups. Given these significant findings, the researchers also explored whether any significant differences between child-self-reported and parent-proxy-reported traumatic stress symptoms existed within each separate disease group. As shown, paired-samples t-tests did not reveal significant differences between child-self-reported and parent-proxy-reported traumatic stress symptoms in the pre-transplant ($t = 1.78$, $p = 0.11$), HIV ($t = 1.12$, $p = 0.29$), or sickle cell disease ($t = 1.29$, $p = 0.21$) group when examining each group individually.

Aim 3: To Determine Possible Predictors of Children's Posttraumatic Stress Symptoms

For the next four hierarchical regression analyses, related demographic variables, including parent age, child minority status, and length of longest hospitalization were entered into the first block of each regression equation. Predictor variables, either child physical status (FDI score) or parent self-reported traumatic stress symptoms (IES-R score), were entered into the second block of each regression equation to test their effect on each dependent variable (child PTSRI total score or parent PTSRI total score).

Child self-reported traumatic stress

Two separate hierarchical regression equations were completed to predict child self-reported traumatic stress (child PTSRI score). To examine the relationship between *child physical status* and *child self-reported traumatic stress* symptoms, child physical status (FDI score) was entered into the second block of the model. The overall regression model predicting youth-reported traumatic stress was not significant ($R^2 = 0.25$, F [4, 25] = 1.72, $p = 0.18$). As shown in Table 3-5, block one of the regression analysis showed a non-significant direct effect for parent age (β =-0 .03, $t = -0.13$, $p = 0.90$), a non-significant direct effect for child minority status ($\beta = 0.002$, $t = 0.01$, $p = 0.99$), and a significant negative direct effect for longest

hospitalization (β = -0.51, t = -2.32, p = 0.03). Block two showed a non-significant direct effect for child physical status (β = 0.05, t = 0.26, p = 0.80).

To examine the relationship between *parent self-reported traumatic stress* and *child self-reported traumatic stress symptoms*, parent self-reported traumatic stress (IES-R score) was entered into the second block of the regression model. The overall model predicting youth-reported traumatic stress was not significant (R^2 = 0.45, F [4, 27] = 1.52, p = 0.23). As shown in Table 3-5, block one of the regression analysis showed a non-significant direct effect for parent age (β = 0.01, t = 0.02, p = 0. 98), a non-significant direct effect for child minority status (β = -0.01, t = -0.05, p = 0.97), and a non-significant direct effect for longest hospitalization (β = -0.43, t = -2.07, p = 0.05). Block two showed a non-significant direct effect for parent self-reported traumatic stress symptoms (β = 0.19, t = 1.00, p = 0.33).

In summary, no main effect for either child physical functioning or parent-self-reported traumatic stress symptoms was found; however, length of the child's longest hospitalization was significant when child functional status was entered into the model and approached significance when parent-self-reported traumatic stress symptoms was entered into the model. Children with a greater number of days spent in the hospital reported fewer traumatic stress symptoms.

Parent-proxy-reported traumatic stress

Two separate hierarchical regression equations were completed to predict parent-proxy-reported traumatic stress symptoms (parent PTSRI total score). To examine the relationship between *child physical status* and *parent-proxy-reported traumatic stress symptoms*, child physical status (FDI total) was entered into the second block of the model. The overall regression model predicting parent-proxy-reported traumatic stress was not significant (R^2 = 0.19, F [4, 34] = 1.80, p = 0.16). As shown in Table 3-6, block one of the regression analysis showed a non-significant direct effect for parent age (β = 0.23, t = 1.42, p = 0.17), a non-

significant direct effect for child minority status ($\beta = 0.24$, $t = 1.42$, $p = 0.17$), and a non-significant direct effect for longest hospitalization ($\beta = 0.01$, $t = 0.80$, $p = 0.94$). Block two showed a significant positive effect for child physical status ($\beta = 0.38$, $t = 2.18$, $p = 0.04$).

To examine the relationship between *parent self-reported traumatic stress* and *parent-proxy-reported traumatic stress symptoms*, parent self-reported traumatic stress (IES-R total) was entered into the second block of the regression model. The overall model predicting parent-proxy-reported traumatic stress was not significant ($R^2 = 0.10$, F [4, 36] = 0.93, $p = 0.46$). As shown in Table 3-6, block one of the regression analysis showed a non-significant direct effect for parent age ($\beta = 0.18$, $t = 1.07$, $p = 0.29$), a non-significant direct effect for child minority status ($\beta = 0.09$, $t = 0.52$, $p = 0.61$), and a non-significant direct effect for longest hospitalization ($\beta = 0.12$, $t = 0.68$, $p = 0.50$). Block two showed a non-significant direct effect for parent self-reported traumatic stress symptoms ($\beta = 0.20$, $t = 1.17$, $p = 0.25$).

In summary, neither overall model including either child physical functioning or parent-self-reported traumatic stress symptoms was found that significantly predicted parent-proxy-reported traumatic stress symptoms; however, child's functional status was significant when entered into the model. Parents of children with greater functional impairment reported that their children experienced greater traumatic stress symptoms.

Parent self-reported traumatic stress

An exploratory hierarchical regression analysis was completed to determine possible predictors of *parent-self reported traumatic stress*. Similar to previous analyses, demographic variables (parent age, child minority status, and length of longest hospitalization) were entered into the first block of the model and *child functional status* was entered into the second block of the model. A hierarchical regression equation was completed to predict parent self-reported traumatic stress symptoms. The overall regression model predicting parent self-reported

traumatic stress was not significant ($R^2 = 0.18$, F [4,38] = 1.87, $p = 0.14$). Block one of the regression analysis showed a non-significant direct effect for parent age ($\beta = 0.19$, $t = 1.25$, $p = 0.22$), a non-significant direct effect for child minority status ($\beta = -0.002$, $t = -0.01$, $p = 0.99$), and a non-significant direct effect for longest hospitalization ($\beta = -0.09$, $t = -.59$, $p = 0.56$). Block two showed a significant positive effect for child physical status ($\beta = .39$, $t = 2.43$, $p = 0.02$).

In summary, the overall model predicting parent-proxy-reported traumatic stress symptoms was not significant; however, child's functional status showed a significant positive main effect when entered into the model. Parents of children with greater functional impairment reported greater traumatic stress symptoms by self-report.

Secondary Aims

Aim 4: To Examine the Quality of Life of Pre-Transplant Candidates

The researchers conducted descriptive statistics to determine the quality of life of pediatric transplant candidates. Table 3-7 shows the means and standards deviations for the current study's pre-transplant disease group and previously published data for healthy and chronically ill children (Varni et al., 2001). Independent samples t-tests found significant differences in the quality of life of pre-transplant candidates to the healthy and chronically ill populations. Specifically, parents of pediatric transplant candidates reported that their child experienced significantly worse quality of life than *healthy* children across all domains of quality of life: physical functioning ($t = -8.75$, $p < .001$), emotional functioning ($t = -3.67$, $p < .001$), social functioning ($t = -8.51$, $p < .001$), school functioning ($t = -7.33$, $p < .001$), psychosocial summary score ($t = -8.17$, $p < .001$), and overall quality of life ($t = -9.55$, $p < .001$). Parents also reported that pediatric transplant candidates experienced worse quality of life than *chronically ill* youth across most domains of quality of life: physical functioning ($t = -3.10$, $p < .01$), social

functioning (t = -3.47, p < .001), school functioning (t = -3.16, p < .01), psychosocial summary score (t = -4.34, p < .001), and overall quality of life (t = -3.67, p < .001).

Pediatric transplant candidates themselves also described their quality of life as worse than *healthy* children across all domains of quality of life: physical functioning (t = -4.92, p < .001), emotional functioning (t = -3.63, p < .001), social functioning (t = -2.95, p < .01), school functioning (t = -2.32, p < .001), psychosocial summary score (t = -4.15, p < .001), and overall quality of life (t = 4.51, p < .001). Pediatric transplant candidates also described their quality of life as worse than *chronically ill* children across several domains of quality of life: physical functioning (t = -2.92, p < .001), emotional functioning (t = -2.56, p < .05), psychosocial summary score (t = -2.78, p < .01), and overall quality of life (t = -2.93, p < .01).

Aim 5: To Examine the Family Functioning of Pre-Transplant Candidates' Families

The researchers conducted descriptive statistics to determine the family functioning of pediatric transplant candidates using previously published clinical cut-offs. Table 3-8 shows the means and standards deviations for the current study's pre-transplant disease group and previously published data for non-clinical and medical populations (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Table 3-9 shows the cut-off scores for unhealthy functioning and the percentage of the current sample that fell in the unhealthy range of family functioning for each subscale of the measure. Using these previously published clinical cut-offs (Ryan et al., 2005) 4.8% of families fell in the unhealthy range of functioning in the Problem Solving domain, 23.8% of families in the Communication domain, 55.0% of families in the Roles domain, 14.3% of families in the Affective Responsiveness domain, 45.0% of families in the Affective Involvement domain, 26.3% of families in the Behavior Control domain, and 45.0% of families in the General Functioning domain fell in the unhealthy range of family functioning.

Independent samples t-tests using the means and standard deviations as shown in Table 3-8 found some significant differences in the family functioning of pre-transplant candidates to the non-clinical and medical populations. Specifically, families of pediatric transplant candidates reported significantly better functioning in the Behavioral Control domain than both the non-clinical ($t = 3.54$, $p < 0.001$) and medical ($t = 2.65$, $p < 0.01$) populations and better functioning in the Affective Responsiveness domain than both the non-clinical ($t = 2.20$, $p < 0.05$) and medical ($t = 2.22$, $p < 0.05$) populations. In addition, families of pediatric transplant candidates reported significantly better functioning in the Communication domain than the medical ($t = 3.50$, $p < 0.001$) population.

Table 3-1. Descriptive statistics among variables of interest

		n	*M*	*SD*
FDI total	Transplant	17	9.24	12.93
	HIV	13	2.23	2.65
	SCD	28	6.61	10.60
	Total	51	6.39	10.39
IES-R total	Transplant	21	17.57	17.09
	HIV	13	11.38	12.65
	SCD	28	14.46	18.29
	Total	62	14.87	16.75
Parent PTSRI total	Transplant	18	10.94	9.62
	HIV	13	13.54	11.69
	SCD	26	10.19	10.81
	Total	57	11.19	10.55
Child PTSRI total	Transplant	14	18.79	13.58
	HIV	12	18.08	15.22
	SCD	19	15.53	12.86
	Total	45	17.22	13.50

Note: Higher scores on the IES-R, parent PTSRI, and child PTSRI suggest greater traumatic stress symptoms. Higher scores on the FDI suggest greater functional disability.

Table 3-2. Correlations between variables of interest across disease groups

	1.	2.	3.	4.	5.	6.
1. Child gender	-					
2. Child age	.10	-				
3. Child minority race	-.08	-.03	-			
4. FDI total	.13	.08	-.10	-		
5. IES-R total	.26	.12	.15	.05	-	
6. Parent PTSRI total	.17	.27*	.25	.18	.27*	-
7. Child PTSRI total	-.05	-.09	.02	-.04	.14	.48**

* $p < .05$, ** $p < .01$

Table 3-3. Percentage of sample meeting clinical cut-off for PTSD diagnoses

		%
IES-R total	Transplant	14.3
	HIV	7.7
	SCD	14.3
	Total	12.9
Parent PTSRI total	Transplant	18.8
	HIV	15.4
	SCD	19.0
	Total	18.0
Child PTSRI total	Transplant	15.4
	HIV	8.3
	SCD	6.7
	Total	10.0

Table 3-4. Differences in child-self-reported and parent proxy-reported traumatic stress

	Child Self-Report		Parent-Proxy Report			
	M	*SD*	*M*	*SD*	*r*	*t*
Transplant	18.79	13.58	10.94	9.62	.54	1.78
HIV	18.08	15.22	13.54	11.69	.44	1.12
SCD	15.53	12.86	10.19	10.81	.51*	1.29
Total	17.22	13.50	11.19	10.55	.48*	2.39**

* $p < .05$, ** $p < .01$

Table 3-5. Hierarchical regression analysis predicting child self-reported traumatic stress

DV: Child PTSRI	β	B	t	$R^2\Delta$	Total R^2
Model 1					
Block 1					
Parent age	-.03	-.001	-.13		.25
Child minority status	.002	.002	.009		
Hospitalization	-.51	-.008	-2.32*		
Block 2					
FDI	.05	.04	.26	.002	.25
Model 2					
Block 1					
Parent age	.01	<.01	.02		.17
Child minority status	-.01	-.01	-.05		
Hospitalization	-.43	-.01	-2.07		
Block 2					
IES-R	.19	.12	1.00	.03	.21

* $p < .05$

Table 3-6. Hierarchical regression analysis predicting parent-proxy-reported traumatic stress

DV: Parent PTSRI	β	B	t	$R^2\Delta$	Total R^2
Model 1					
Block 1					
Parent age	.23	.01	1.42		.07
Child minority status	.24	.28	1.42		
Hospitalization	.01	<.01	.08		
Block 2					
FDI	.38	.29	2.18*	.13	.19
Model 2					
Block 1					
Parent age	.18	.01	1.07		.06
Child minority status	.09	.10	.52		
Hospitalization	.12	.001	.68		
Block 2					
IES-R	.20	.13	1.17	.04	.10

* $p < .05$

Table 3-7. Comparison of quality of life of pediatric transplant candidates to the healthy and chronically ill pediatric populations

	Transplant		Chronically Ill[a]		Healthy[a]	
	M	*SD*	*M*	*SD*	*M*	*SD*
Parent PedsQL						
Physical score	51.46	26.06	73.28	27.02	89.32	16.35
Emotional score	65.83	17.97	73.05	23.27	82.64	17.54
Social score	60.00	15.24	79.77	21.91	91.56	14.20
School score	51.22	26.97	71.08	23.99	85.47	17.61
Psychosocial summary score	59.11	17.01	74.80	18.16	86.58	12.79
Total score	56.60	17.54	74.22	18.40	87.61	12.33
Child PedsQL						
Physical score	61.13	21.73	77.36	20.36	84.41	17.26
Emotional score	61.43	21.88	76.40	21.48	80.86	19.64
Social score	73.57	19.94	81.60	20.24	87.42	17.18
School score	65.54	25.84	73.43	19.57	78.63	20.53
Psychosocial summary score	65.68	21.62	77.10	15.84	82.38	15.51
Total score	64.70	18.28	77.19	15.53	83.00	14.79

Note: Higher scores on the parent and child PedsQL suggest better quality of life.
[a] Varni et al., 2001

Table 3-8. Comparison of family functioning of pediatric transplant candidates to the non-clinical and medical population

	Transplant		Non-clinical[a]		Medical[a]	
	M	*SD*	*M*	*SD*	*M*	*SD*
Problem solving	1.88	0.30	1.91	.40	1.95	.45
Communication	1.99	0.43	2.09	.40	2.13	.43
Roles	2.28	0.24	2.16	.34	2.22	.39
Affective responsiveness	1.82	0.43	2.08	.53	2.08	.53
Affective involvement	2.01	0.38	2.00	.50	2.02	.47
Behavior control	1.58	0.39	1.94	.44	1.84	.42
General functioning	1.81	0.40	1.84	.43	1.89	.45

Note: Higher scores on the FAD suggest more maladaptive family functioning.
[a] Ryan et al., 2005

Table 3-9. Percentage of sample meeting clinical cut-off for unhealthy family functioning

	Cut-off Score	%
Problem solving	2.20	3.8
Communication	2.20	23.8
Roles	2.30	55.0
Affective responsiveness	2.20	14.3
Affective involvement	2.10	45.0
Behavior control	1.90	26.3
General functioning	2.00	45.0

CHAPTER 4
DISCUSSION

Our study adds needed research to the existing literature examining traumatic stress in pediatric chronic illness populations. Given the limited number of existing studies in this area, it was important to continue to explore the traumatic stress symptoms of both children and their parents in the pediatric chronic illness population. Examining not only the prevalence of traumatic stress symptoms in three separate pediatric chronic illness groups, our study also directly compared traumatic symptoms between each of the three illness groups, evaluated differences in children self-reported and parent-proxy-reported traumatic stress symptoms, and attempted to determine possible predictors of traumatic stress symptoms in the pediatric transplant, HIV, and sickle cell populations. In addition, our study explored in greater depth the quality of life and family functioning of pediatric transplant candidates.

Findings Regarding Traumatic Stress

Although differences were not significant between groups by parent-proxy and parent-self-report, a significant difference in traumatic stress symptoms was observed between different chronic illness groups by child self-report. That pediatric transplant candidates reported they experienced greater traumatic stress symptoms than children diagnosed with HIV on a self-report measure of traumatic stress symptoms provides important preliminary evidence that particular pediatric chronic illness populations may indeed experience greater traumatic stress symptoms than do other chronic illness groups. This significant difference in traumatic stress symptoms was found despite the low overall rates of traumatic stress symptoms children reported. However, the low overall rates of traumatic stress (i.e., only a minority of individual reported symptoms of stress suggestive of a diagnosis of PTSD) may also account for the lack of significant differences by parent-proxy and parent-self-report. Overall, most individuals reported

sub-clinical levels of traumatic stress and obtained lower scores on each of the traumatic stress measures. This suggests that, overall, children and parents seem to be coping reasonably well with the child's chronic illness.

Despite the lack of differences in traumatic stress symptoms by parent-proxy and parent self-report, the finding of a significant difference in child self-reported traumatic stress symptoms suggests that pediatric transplant candidates experience greater traumatic stress symptoms than children diagnosed with HIV and that the transplant process is perceived as more traumatic. While not a statistically significant group difference in preliminary analyses, perhaps the shorter time since diagnosis for transplant candidates (M = 56.21, SD = 68.31) compared to children diagnosed with HIV (M = 125.33, SD = 58.96) helps to explain this difference. A number of children currently diagnosed with HIV are diagnosed at birth (Centers for Disease Control and Prevention, 2005) and have had longer to adjust to their illness, prognosis, and treatment course than children and families being considered for transplant who face a more uncertain treatment course and outcome (Engle, 2001).

Contrary to expectations, neither the model including child functional status nor the model including parent self-reported traumatic stress scores significantly predicted child-self reported or parent-proxy-reported traumatic stress. This lack of relationship is surprising given the previous research in this area which found that child and parent traumatic stress symptoms were positively related to each other (Schreier et al., 2005, Shemesh, Newcorn, et al., 2005) and functional status predicted child and parent traumatic stress symptoms (Landolt et al., 2003). Functional status may be more important for children who are currently hospitalized as are those often studied in the pediatric injury literature (Schreier et al., 2005). It may also be that the low overall rates of parent traumatic stress and child functional impairment made it more difficult to

find a significant relationship. Perhaps, this lack of significant relationship suggests that other variables are accounting for the differences in traumatic stress in these populations.

This may be especially true given that analyses did reveal individual main effects when independently examining each of the variables. For example, child functional status was significantly related to parent-proxy-reported traumatic stress symptoms and parent self-reported traumatic stress symptoms suggesting that the physical or functional impact of a disease may be adversely related to traumatic stress. Parents of children may be especially susceptible to traumatic stress symptoms as they care for a child whose functional status is negatively affected by their condition. Regardless, future research should continue to explore other possible predictors of traumatic stress symptoms. For children coping with a chronic illness on an outpatient basis, perceived life threat or prognosis may be possible variables that are predictive of traumatic stress symptoms. Previous researchers found that these variables were related to traumatic stress symptoms in the pediatric oncology populations (Hobbie et al., 2000) and suggest possible predictors of traumatic stress to be investigated in future studies in the pediatric transplant, HIV, and sickle cell disease areas.

That length of the child's longest hospitalization also differed significantly between groups may provide additional support regarding the importance of life threat in understanding the traumatic stress symptoms chronically ill children may experience. Given previous literature suggesting that life threat is associated with greater traumatic stress symptoms in the pediatric oncology population (Hobbie et al., 2000), the use of hospitalization length as a variable in our study may be indicative of greater life threat for youth. Interestingly, while longer hospitalizations were related to fewer traumatic stress symptoms across groups, hospitalizations, especially hospitalizations longer in duration, are suggestive of serious complications and

perhaps greater life threat. Compared to children diagnosed with HIV (M=13.14, SD = 21.08) and children diagnosed with sickle cell disease (M = 9.00, SD = 12.60), pediatric pre-transplant candidates (M = 45.59, SD = 53.85) experienced longer hospitalizations on average. This difference, in combination with the acute life threat associated with pediatric transplantation documented in previous literature (Engle, 2001), may explain our study's findings. At the time of their pre-transplant evaluation, many pediatric transplant candidates had already faced a lengthy chronic illness that had not responded to other treatment approaches in addition to continuing to face the uncertainty of the actual transplantation procedure and post-transplant recovery.

Despite the lack of significant group differences in traumatic stress symptoms by parent-proxy-report and parent self-report, the majority of both child and parent participants reported at least some traumatic stress symptoms regardless of disease group and across informants. In addition, overall rates of traumatic stress symptoms were similar to those previously reported in the pediatric oncology literature using the same measures (Kazak, Alderfer, Rourke, et al., 2004). As shown in Table 4-1, youth across disease groups reported similar levels of traumatic stress symptoms by both child self-report and parent proxy-report compared to survivors of pediatric cancer. In contrast, parents of children diagnosed with HIV and sickle cell disease reported fewer symptoms than parents of pediatric cancer survivors ($p < .05$).

While a minority, a number of participants also reported traumatic stress symptoms suggestive of a diagnosis of PTSD. This is similar to the limited research in area, which has documented traumatic stress symptoms across all three chronic illness populations, including pediatric transplantation (Farley et al., 2007; Manne et al., 2004; Shemesh et al., 2000; Walker et al., 1999; Young et al., 2003), pediatric HIV (Radcliffe et al., 2007), and pediatric sickle cell

disease (Hofmann et al., 2007). The lack of significant differences by parent-proxy-report and parent self-report may suggest that, for parents especially, coping with any pediatric chronic illness may be difficult and it is the illness in general, rather than specific disease-related variables, that account for the traumatic stress symptoms they experience. Certainly, research across disease groups supports the notion that parenting a child with a chronic medical condition can be a traumatic experience (Balluffi et al., 2004).

Interestingly, across disease groups, children and parents reported significantly different rates of child traumatic stress symptoms, although rates remained positively correlated with one another. Given the mixed research previously published in this area, this finding is not entirely surprising. While some researchers have not documented significant differences between child self-reported and parent-proxy-reported psychosocial functioning (Nuss & Wilson, 2007; Phipps et al., 2005), other researchers have documented such differences between informants (Panepinto et al., 2005; Shemesh, Annunziato, et al., 2005). In fact, differences in child and parent-proxy-reports of functioning found in our study are similar to those previously published in the oncology population (Kazak, Alderfer, Rourke, et al., 2004) providing additional support for differences in reported functioning by informant. It may be that the symptoms of traumatic stress are difficult for parents to observe in their children and account for the difference in rates of traumatic stress across informants. For example, researchers in other populations (Connolly & Johnson, 1999; Drotar, 2004) have found that reports from parents are often more similar to children's self-reported functioning when describing physical or externalizing dimensions (e.g., oppositional behaviors) of functioning and are less similar when describing internalizing dimensions (e.g., depressive symptoms). This seems to be a true for our study, where examination of responses revealed that a number of families chose the "I don't know" option

when answering questions regarding their children's traumatic stress symptoms. That parents and children reported different rates of symptoms suggest that parents may not always be accurate informants regarding their children's traumatic stress or know what traumatic stress symptoms their child may be experiencing. This may be especially important to consider when obtaining rates of symptoms by child self-report is not possible, either because of child age or physical status. This is especially true in our study, which included a greater number of parents who completed parent-proxy measures of child traumatic stress symptoms than children who completed self-report measures. A number of children were under eight years of age; without use of parent-proxy measures no assessment of child traumatic stress symptoms would have been possible. While information from parents is certainly valuable and better than no information regarding child functioning at all, our study suggests that reliance on parents' report of symptomatology exclusively may prevent some children from receiving needed psychosocial services.

Findings Regarding Pediatric Transplantation

Our study also added to the existing literature in pediatric transplantation by exploring both the quality of life and family functioning of pediatric transplant candidates. Overall, the quality of life of pediatric candidates was worse than that of healthy or non-clinical populations and more similar to chronically ill or medical populations. This finding is similar to that previously reported in the pediatric liver transplant population where children reported low overall quality of life (Taylor et al., 20005b), but quality of life that was similar to other pediatric chronic illness populations (Taylor et al., 2005a). These findings suggest that, compared to the healthy population, the pediatric transplant process adversely affects the functioning of youth and their families. That the quality of life of these youth is lower than healthy children is not surprising when considering previous research that suggests significant academic, physical, and

psychosocial consequences related to the transplant process. That the quality of life of these youth was also less than that of the chronically ill population across many dimensions provides further evidence regarding the significant psychosocial consequences that these youth face. Overall, the finding of lower quality of life in this population is similar to findings in other pediatric illnesses where researchers have documented the negative impact of a number of different pediatric diseases on children's quality of life (Varni, Limbers, & Burwinkle, 2007). For example, lower quality of life has been reported in the pediatric obesity (Zeller, Roehrig, Modi, Daniels, & Inge, 2005), cancer (Varni, Burwinkle, & Katz, 2004), diabetes (Varni, Burwinkle, Jacobs et al., 2003), and asthma (Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004) literature compared to that reported in healthy populations.

In addition to reports of lower quality of life and similar to the significant caregiver and family stress reported by parents of solid organ and bone marrow transplant candidates (Rodrique et al., 1997), a number of parents of pediatric transplant candidates described their family functioning as falling in the unhealthy range across a number of dimensions of functioning. In contrast, despite difficulties for some families, families on average reported better functioning than the non-clinical and medical populations across several dimensions of functioning. Specific strengths in behavioral control and affective responsiveness compared to both the medical and non-clinical population suggest that families of transplant candidates appropriately express their emotions in relation to certain situations and flexibly maintain and adapt their behaviors. In addition, results suggest that transplant candidate families clearly and directly communicate with one other compared to medical families (Ryan et al., 2005). These results are surprising given previous research in the area that suggests that coping with a chronic illness may negatively impact a family's functioning (Pai et al., 2007). It may be that, for some

families, the nature of the transplant process (i.e., close contact with family members, a structured assessment protocol, and opportunities for decision making) leads to greater interactions and better functioning across some domains. For example, families coping with an event that they have previously described as traumatic learn more appropriate ways to express their feelings in relation to the stressful situation.

Despite the relative strengths in transplant family functioning compared to previously published normative data, a number of individual families fell in the unhealthy range of family functioning using previously published clinical cut-off data (Ryan et al., 2005). It seems that while the family functioning of most pediatric transplant families is similar to or better than other populations, for some families, family functioning may be adversely impacted by the transplant process. Previous researchers have documented a unidirectional relationship between family functioning and pediatric chronic illness such that the specific chronic illness may result in greater family conflict following diagnosis (Pai et al., 2007). On the other hand, this relationship may also be bi-directional. For example, other researchers have found that impaired family functioning is related to poorer adherence in medical populations (Ryan et al., 2005), which may have resulted in the eventual need for organ transplantation due to lack of compliance with a specified treatment regimen. Regardless of the direction of the effect, impairments in family functioning reported by a number of parents of pediatric transplant candidates may place these families at greater risk for additional psychosocial and medical difficulties as they cope with the child's illness (DeMaso et al., 1995).

Although specific differences in both quality of life and family functioning were found compared to the healthy or non-clinical populations, fewer overall differences were found when comparing the general functioning of pediatric transplant candidates to the chronically ill

population. This is in contrast to the significant differences in child-self reported traumatic stress symptoms found between transplant candidates and children diagnosed with HIV and suggests that the quality of life and family functioning of transplant candidates may be more similar to other chronically ill children. It may be that, across dimensions of general functioning, chronically ill youth appear more similar to each other. However, disease specific measures of quality of life (Varni, Burwinkle, Jacobs et al., 2003) and family functioning (Lewin et al., 2006), such as those created for the pediatric diabetes populations, are likely more sensitive in detecting more subtle differences across populations and more fully describe the unique issues that youth in a particular disease group might face. Such measures might be especially valuable in order to examine possible differences within disease groups. While not possible due to limited sample size in our study, future studies might also explore possible within group differences, such as possible differences in the quality of life and family functioning, within separate pediatric transplant groups (i.e., solid organ compared to bone marrow transplantation) using such disease specific measures.

Strengths of the Study

Our study included several unique elements that have not previously been included in the traumatic stress literature. First, our study assessed traumatic stress symptoms of children by both youth self-report and parent-proxy-report, in addition to measuring the traumatic stress symptoms of parents themselves. Such measurement provides a more comprehensive examination of the psychosocial functioning of families as a whole. Given previous literature in pediatric cancer suggesting that at least one member of a family experiences some traumatic stress symptoms during the course of a child's illness (Kazak, Alderfer, Rourke, et al., 2004), measurement of both child and parent symptoms is increasingly necessary and informative in regard to understanding a family's overall psychological functioning. In addition, measurement

of children's psychological symptoms by both self-report and parent-proxy-report provides a straightforward compromise to the continuing debate in the field regarding the best informant (i.e., parents or children themselves) for describing children's symptoms (Eiser & Morse, 2001).

Second, our study attempted to determine possible predictors of traumatic stress in the pediatric population. While some researchers have begun to examine possible factors related to traumatic stress in the pediatric populations (Hobbie et al., 2000; Holbrook et al., 2005; Landolt et al., 2003; Shemesh, Newcorn, et al., 2005), the majority of existing research is descriptive in nature and includes few other variables of interest. Despite the lack of statistically significant findings, the relatively large effect sizes suggest the importance of re-examining these variables in future studies recruiting larger numbers of families.

Third, our study included three separate pediatric chronic illness populations: transplantation, HIV, and sickle cell disease. While several researchers have recognized the promise of a model of traumatic stress in understanding pediatric chronic illness, few researchers have directly compared traumatic stress symptoms across separate disease groups (Kassam-Adams, 2008). Given the wide range of measurement tools available to describe traumatic stress symptoms, making any comparisons across different studies is exceedingly difficult. This study provides evidence across separate disease groups that parents and children, regardless of disease, experience some traumatic stress symptoms. Furthermore, that children and parents reported symptoms across all three chronic illness groups suggests that coping with a pediatric illness can be a traumatic experience for families regardless of the regimens, prognoses, and treatments that are specific to their particular condition or diagnosis.

Limitations

Despite our study's strengths, it is also important to recognize certain limitations inherent in our study. First, the small sample size limited the number of variables that were tested. In

addition, data was missing for a number of participants, especially in the pediatric transplant disease group. However, our study's sample is similar to other studies in this area and is reflective of the national prevalence of relatively rare conditions (e.g., 2000 pediatric solid organ transplants per year nationally). This speaks to the increasing need for multi-site research and greater collaboration among pediatric researchers across institutions. Given the relatively large effect sizes found despite the lack of statistical significance, future studies recruiting larges samples will likely have greater power to detect statistically significant results. Certainly, future research would benefit from recruitment of participants across several pediatric clinical practices and hospitals. Second, there was also significant variability between participants in our study. While significant differences in demographic variables were controlled for in subsequent analyses, this may have made it more difficult to perceive differences in the variables of interest between the three chronic illness populations. In addition, participants' motivation while completing the questionnaires may have differed across disease groups. For example, pediatric transplant candidates and their families may have felt pressured to mask any difficulties they were having for fear it would impact the pre-transplant evaluation process and final medical decisions regarding transplantation. Third, the majority of parents and children reported sub-clinical levels of traumatic stress symptoms. This decreased the variance in traumatic stress symptoms and resulted in a negatively skewed distribution. While the impact was lessened by statistically transforming the populations in question to more closely resemble a normal distribution, the resulting transformation also makes it more difficult to draw conclusions regarding the various relationships examined. Fourth, the generalizability of our study's findings should be considered carefully. Of note, both the small samples recruited and limited assessment batteries limit the conclusions that can be drawn regarding the functioning of pediatric

populations in other areas or the functioning of children and families over time. For example, only children with knowledge of their HIV diagnosis were included in our study. Certainly, children with no knowledge of their diagnosis may have reported different symptoms of traumatic stress than those who do. Lastly, the quality of life and family functioning measures were administered only in the pediatric pre-transplant population. Certainly, assessing both of these domains in both the HIV and sickle cell disease populations would have been ideal; however, the inclusion of these measures was not possible at this time. Physicians in both clinics asked that the amount of data collection be limited out of respect for the families and clinic staff and to limit the study's possible disruption to the daily clinic routine.

Implications for Clinical Intervention and Research

Understanding the psychosocial functioning of chronically ill youth and their families, especially as it relates to posttraumatic stress, is integral to improving both the psychological functioning and medical outcomes for youth coping with chronic and life threatening medical conditions. That most parents and children in our study, regardless of their condition, reported at least some traumatic stress symptoms suggests that a model of intervention similar to the model proposed by Kazak and colleagues (National Traumatic Stress Network, 2005) may be an appropriate model to use to intervene with families by matching the intensity of services with individual family needs. Such a model answers the need proposed by previous researchers (Barlow & Ellard, 2004) for a single framework to guide future research and intervention work in the area. Similar to the research in traumatic stress in other pediatric populations (Barakat et al., 2006; Best et al., 2001; Kazak, Alderfer, Rourke, et. al., 2004; Kazak et al., 2005; Rourke et al., 1999), assessing the psychosocial functioning of both youth and their families provides researchers and clinicians an important opportunity to identify youth and families at-risk for later difficulties and to plan appropriate interventions to decrease the prevalence of these difficulties.

Indeed, the benefit of a model of traumatic stress in planning clinical interventions in these populations is that it provides services to families experiencing both clinical and sub-clinical levels of symptomatology (Kazak, 2001; Kazak, Alderfer, Streisand, et al., 2004; Stuber et al., 2006) and perhaps provides clinicians an opportunity to intervene before more serious psychological difficulties occur. That a number of families in our study reported symptoms of traumatic stress suggestive of an actual clinical diagnosis of PTSD provides even greater support for the need for timely and effective interventions in these populations regardless of the specific pediatric condition.

In addition, the finding that longer hospitalizations predicted fewer traumatic stress symptoms is somewhat surprising and suggests that, perhaps for some families, longer hospitalizations provided greater time to adjust to and cope with a chronic illness as a family. In contrast, the finding that children experiencing greater functional impairment experienced greater traumatic stress symptoms by parent-proxy-report suggests that they children may be especially in need of psychological services. Determining other possible predictors of posttraumatic stress symptoms in both children and their parents will help clinicians to target appropriate interventions and modify different psychological, medical, or environmental factors that may contribute to posttraumatic stress symptoms in this population. In addition, determining what psychological factors might differentiate between different chronic illness groups may also help researchers to specify the most appropriate intervention strategy for each population. Given previous research regarding the contribution of individual and family psychological variables to non-adherence, survival rates and prognosis (Bartlett et al., 2004; Dobkin et al., 2000; Fiese & Everhart, 2006; McConville et al., 1990), further study in this area

may help to further elucidate areas of difficulty for these families and, consequently, areas for intervention.

Summary

Our study added to the existing literature in pediatric traumatic stress by directly comparing the traumatic stress symptoms of children and parents across individual disease groups. That children being considered for transplant, children diagnosed with HIV, and children diagnosed with sickle cell disease and their parents reported similar rates of traumatic stress symptoms by parent report suggests that coping with a chronic illness in general can be a stressful experience. That pediatric transplant candidates in particular reported significantly more traumatic stress symptoms than youth diagnosed with HIV suggests traumatic stress may be more critical for certain disease groups. That only a minority of children and families reported symptoms suggestive of a clinical diagnosis of PTSD also suggests that families are generally coping adaptively with this stress. That children and parents reported significantly different rates of child traumatic stress symptoms provides further support regarding the necessity of child self-report measures in accurately assessing children's psychosocial functioning. Our study also found that inpatient hospitalizations were related to children's report of traumatic stress symptoms and child functional impairment was related to parents' report of both their children's symptoms and their own traumatic stress symptoms. Finally, the study explored in greater depth the quality of life and family functioning of pediatric transplant candidates finding that, while significant differences in functioning were reported compared to the healthy populations in most areas, general quality of life and family functioning was more similar to other chronic illness populations. Overall, these findings are significant in that they suggest that a model of intervention, such as that found with the traumatic stress literature, may

be especially informative and effective in that it addresses the needs of families across pediatric conditions and those who report both clinical and sub clinical levels of distress.

Table 4-1. Comparison of traumatic stress symptoms to the pediatric oncology population

		n	*M*	*SD*
IES-R total	Transplant	21	17.57	17.09
	HIV	13	11.38	12.65
	SCD	28	14.46	18.29
	Cancer[a]	146	28.20	24.49
Parent PTSRI total	Transplant	18	10.94	9.62
	HIV	13	13.54	11.69
	SCD	26	10.19	10.81
	Cancer[a]	146	23.89	12.83
Child PTSRI total	Transplant	14	18.79	13.58
	HIV	12	18.08	15.22
	SCD	19	15.53	12.86
	Cancer[a]	150	15.67	12.51

[a] Kazak, Alderfer, Rourke, et al., 2004

LIST OF REFERENCES

Adams-Graves, P., Kedar, A., Koshy, M., Steinberg, M., Veith, R., Ward, D., et al. (1997). RheothRx (poloxamer 188) injection for the acute painful episode of sickle cell disease: a pilot study. *Blood, 90*, 2041-2046.

American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (Text Revision).* Arlington: American Psychiatric Association.

Bachanas, P.J., Kullgren, K.A., Schwartz, K.S., Lanier, B., McDaniel, J.S., Smith, J., et al. (2001). Predictors of psychological adjustment in school-age children infected with HIV. *Journal of Pediatric Psychology, 26*, 343-352.

Balduzzi, A., Gooley, T., Anasetti, C., Sanders J.E., Martin, P.J., Petersdorf, E.W., et al. (1995). Unrelated donor marrow transplantation in children. *Blood, 15,* 3247-3256.

Balluffi, A.L., Kassam-Adams, N.P., Kazak, A.P., Tucker, M., Dominguez, T., & Helfaer, M. (2004). Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatric Critical Care Medicine, 5*, 547-553.

Barakat, L.P., Alderfer, M.A., & Kazak, A.E. (2006). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology, 31*, 413-419.

Barlow, J. H. & Ellard, D.R. (2004). Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child: Care, Health, and Development, 30*, 637-645.

Barlow, J.H. & Ellard, D.R. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child: Care, Health, and Development, 32*, 9-31.

Bartlett, S.J., Krishnan, J.A., Riekert, K.A., Butz, A.M., Malveaux, F.J., & Rand, C.S. (2004). Maternal depressive symptoms and adherence to terapy in inner-city children with asthma. *Pediatrics, 113*, 229-237.

Best, M., Streisand, R., Catania, L., & Kazak, A.E. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology, 26*, 299-307.

Bethell, C.D., Read, D., Blumberg, S.J., & Newacheck, P.W. (2008). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal, 1*, 1-14.

Bihun, J.T., Wamboldt, M.Z., Gavin, L.A., & Wamboldt, F.S. (2002). Can the Family Assessment Device (FAD) be used with school aged children? *Family Process, 41*, 723-731.

Boekaerts, M. & Röder I. (1999). Stress, coping, and adjustment in children with a chronic disease: a review of the literature. *Disability and Rehabilitation, 21*, 311-337.

Bose, S., Moss, H., Brouwers, P., Pizzo, P., & Lorion, R. (1994). Psychologic adjustment of human immunodeficiency virus-infected school-age children. *Journal of Developmental & Behavioral Pediatrics, 15*, S34.

Brosig, C.L. (2003). Psychological functioning of pediatric lung transplant candidates/recipients: A review of the literature. *Pediatric Transplantation, 7*, 390-394.

Brown, R.T., Connelly, M., Rittle, C., Clouse, B. (2006). A longitudinal examination predicting emergency room use in children with sickle cell disease and their caregivers. *Journal of Pediatric Psychology, 31*, 163-173.

Brown, R.T., Kaslow, N.J., Doepke, K., Buchanan, I., Eckman, J., Baldwin. K., & Goonan, B. (1993). Psychosocial and family functioning in children with sickle cell syndrome and their mothers. *Journal of the American Academy of Child and Adolescent Psychiatry, 32*, 545-553.

Burlew, K., Telfair, J., Colangelo, L., & Wright, E.C. (2000). Factors that influence adolescent adaptation to sickle cell disease. *Journal of Pediatric Psychology, 25*, 287-299.

Byrne, M.W. & Honig, J. (2006). Health-related quality of life of HIV-infected children on complex antiretroviral therapy at home. *Journal of the Association of Nurses in AIDS Care 17*, 27-35.

Cadman, D., Rosenbaum, P., Boyle. M., & Offord, D.R. (1991). Children with chronic illness: family and parent demographic characteristics and psychosocial adjustment. *Pediatrics, 87*, 884-889.

Centers for Disease Control and Prevention (2005). *HIV/AIDS Surveillance Report*. Retrieved January 3, 2008, from http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/ default.htm

Cohen, D.M., Lumley, M.A., Naar-King, S., Partridge, T., & Cakan, N. (2004). Child behavior problems and family functioning as predictors of adherence and glycemic control in economically disadvantaged children with type 1 diabetes: A prospective study. *Journal of Pediatric Psychology, 29*, 171-184.

Connolly, M.A. & Johnson, J.A. (1999). Measuring quality of life in paediatric patients. *Pharmacoeconomics, 16,* 605-625.

Creamer, M., Bell, R., & Failla, S. (2003). Psychometric properties of the Impact of Event Scale - Revised. *Behavior Research and Therapy, 41*, 1489-1496.

Cuffe, S.P., Addy, C.L., Garrison, C.Z., Waller, J.L., Jackson, K., McKeown, R.E., et al. (1998). Prevalence of PTSD in a community sample of older adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry, 37*, 147-154.

DeMaso, D.R., Kelley, S.D., Bastardi, H., O'Brien, P., & Blume, E.D. (2004). The longitudinal impact of psychological functioning, medical severity, and family functioning in pediatric heart transplant. *Journal of Heart and Lung Transplantation, 23*, 473-480.

DeMaso, D.R., Twente, A.W., Spratt, E.G., & O'Brien, P. (1995). Impact of psychological functioning, medical severity, and family functioning in pediatric heart transplantation. *Journal of Heart and Lung Transplantation, 14*, 1102-1108.

Dixon T.C. & Cunningham, C.K. (2007). Treatment of children with HIV infection. *Current HIV/AIDS Reports, 4*, 93-99.

Dobkin, P.L., Poirier, R.M., Robaey, P., Bonny, Y., Champagne, M., & Joseph, L. (2000). Predictors of physical outcomes in pediatric bone marrow transplantation. *Bone Marrow Transplant, 26*, 553-558.

Drotar, D (2004). Validating measures of pediatric healthy status, functional status, and health-related quality of life: Key methodological challenges and strategies. *Ambulatory Pediatrics, 4*, 358-364.

Dunne M. (2000). Antiretroviral drug development: the challenge of cost and access. *AIDS, 21*, S73-79.

Eiser, C., Mohay, H., & Morse, R. (2000). The measurement of quality of life in young children. *Child: Care, Health, and Development, 26*, 401-414.

Eiser, C. & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research, 10*, 347-357.

Engle, D. (2001). Psychosocial aspect of the organ transplant experience: What has been established and what we need for the future. *Journal of Clinical Psychology, 57*, 521-549.

Epstein, N.B., Baldwin, LM., & Bishop, D.S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy, 9*, 171–180

Farley, L.M., DeMaso, D.R., D'Angelo, E., Kinnamon, C., Bastardi, H., Hill, C.E., Blume, E.D., & Logan, D.E. (2007). Parenting stress and parental post-traumatic stress disorder in families after pediatric heart transplantation. *Journal of Heart and Lung Transplantation, 26*, 120-126.

Fiese, B.H. & Everhart, R.S. (2006). Medical adherence and childhood chronic illness: family daily management skills and emotional climate as emerging contributors. *Current Opinion in Pediatrics, 18*, 551-557.

Fiese, B.H. & Wamboldt, F.S. (2003). Coherent accounts of coping with a chronic illness: convergences and divergences in family measurement using a narrative analysis. *Family Process, 42*, 439-451.

Fotheringham M.J. & Sawyer, M.G. (1995). Adherence to recommended medical regimens in childhood and adolescence. *Journal of Paediatrics and Child Health, 31*, 72-78.

Garralda, M.E. & Rangel, L. (2004). Impairment and coping in children and adolescents with chronic fatigue syndrome: a comparative study with other pediatric disorders. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 45*, 543-552.

Geist, R., Grdisa, V., & Otley, A. (2003). Psychosocial issues in the child with chronic conditions. *Best Practice & Research Clinical Gastroenterology, 17*, 141-152.

Gerson, A.C., Joyner, M., Fosarelli, P., Butz, A., Wissow, L., Lee, S., et al. (2001). Disclosure of HIV diagnosis to children: When, where, why, and how. *Journal of Pediatric Health Care, 15,* 161-167.

Hardy, M.S., Routh, D.K., Armstrong, F.D., Albrecht, J., & Davis, J. (1995). Interpersonal distance and coping in children with HIV and cancer. *Child Health Care, 24*, 119-131.

Health Resources and Services Administration (2006). *2006 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996-2005*. Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation, Rockville, MD.

Hesketh, K.D., Wake, M.A., & Cameron, F.J. (2004). Health-related quality of life and metabolic control in children with type 1 diabetes: a prospective cohort study. *Diabetes Care, 27,* 415-420.

Hintze, J. (2004). NCSS and PASS Number Cruncher Statistical System. Kaysville, Utah.

Hobbie, W.L., Stuber, M., Meeske, K., Wissler, K., Rourke, M.T., Ruccione, K., et al. (2000). Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *Journal of Clinical Oncology, 18*, 4060-4066.

Hofmann, M., Montalembert, M., Beauquier-Maccotta, B., de Villartay, P. & Golse, B. (2007). Posttraumatic stress disorder in children affected by sickle-cell disease and their parents. *American Journal of Hematology 82*, 171–172.

Holbrook, T.L., Hoyt, D.B., Coimbra, R., Potenza, B., Sise, M.J., Sack, D.I., & Anderson, J.P. (2007). Trauma in adolescents causes long-term marked deficits in quality of life: adolescent children do not recover preinjury quality of life or function up to two years postinjury compared to national norms. *Journal of Trauma, 62*, 577-583

Hsu, D.T. (2005). Biological and psychological differences in the child and adolescent transplant recipient. *Pediatric Transplantation, 9*, 416-421.

Ikeda, T., Ch'ng, T.W., & Oleske, J.M. (2007). Recommendations in pediatric antiretroviral therapy. *Expert Opinion on Pharmacotherapy, 8,* 155-166.

Jay, S., Litt, I.F., & Durant, R.H. (1984). Compliance with therapeutic regimens. *Journal of Adolescent Health Care, 5*, 124-136.

Kassam-Adams, N. (2008, April). *Evaluating and Treating Trauma in Pediatric Settings.* Symposium presented at the National Conference on Child Health Psychology, Miami, FL.

Katz, S. & Nevid, J.S. (2005). Risk factors associated with posttraumatic stress disorder symptomatology in HIV-infected women. *AIDS Patient Care STDs, 19*, 110-120.

Kazak, A.E. (2001). Comprehensive care for children with cancer and their families: A social ecological framework guiding research, practice, and policy. *Children's Services: Social Policy, Research and Practice, 4,* 217-233.

Kazak, A.E., Alderfer, M., Rourke, M.T., Simms, S., Streisand, R., & Grossman, J.R. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology, 29*, 211-219.

Kazak, A.E., Alderfer, M., Streisand, R., Simms, S., Rourke, M.T., Hwang W-T, et al. (2004). Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families. *Journal of Family Psychology,* 18, 493-504.

Kazak, A.E., Boeving, C.A., Alderfer, M.A., Hwang, W.T., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology, 23,* 7405-7410.

Kazak, A. E. & Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology, 22*, 149-165.

Kell, R.S., Kliewer, W., Erickson, M.T., Ohene-Frempong, K. (1998). Psychological adjustment of adolescents with sickle cell disease: relations with demographic, medical, and family competence variables. *Journal of Pediatric Psychology,* 23, 301-312.

Landolt, M.A., Vollrath, M., Ribi, K., Gnehm, H.E., & Sennhauser, F.H. (2003). Incidence and associations of parental and child posttraumatic stress symptoms in pediatric patients. *Journal of the American Academy of Child and Adolescent Psychiatry, 44,* 1199-1207.

Lavigne, J.V. & Faier-Routman J. (1992). Psychological adjustment to pediatric physical disorders: a meta-analytic review. *Journal of Pediatric Psychology, 17*, 133-157.

Lavigne, J. V. & Faier-Routman, J. (1993). Correlates of psychological adjustment to pediatric physical disorders: a meta-analytic review and comparison with existing models. *Journal of Developmental and Behavioral Pediatrics, 14,* 117-123.

Lee, M. B, & Rotheram-Borus, M. J. (2002). Parents' disclosure of HIV to their children. *AIDS, 16*, 2201-2207.

Lemanek, K.L., Kamps, J., & Chung, N.B. (2001). Empirically supported treatments in pediatric psychology: Regimen adherence. *Journal of Pediatric Psychology, 26*, 253-275.

Leserman, J., Whetten, K., Lowe, K., Stangl, D., Swartz, M., & Thielman, N.M (2005). How Trauma, Recent Stressful Events, and PTSD Affect Functional Health Status and Health Utilization in HIV-Infected Patients in the South. *Psychosomatic Medicine, 67*, 500-507.

Lewin, A.B., Heidgerken, A.D., Geffken, G.R., Williams, L.B., Storch, E.A., Gelfand, K.M., et al. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Pediatric Psychology, 31*, 174-183.

Lewis, M. & Vitulano. L.A. (2003). Biopsychosocial issues and risk factors in the family when the child has a chronic illness. *Child and Adolescent Psychiatric Clinics of North America, 12,* 389-399.

Logan, D.E., Radcliffe, J., & Smith-Whitley, K. (2002). Parent factors and adolescent sickle cell disease: associations with patterns of health service use. *Journal of Pediatric Psychology, 27*, 475-484.

Logan, D.E. & Scharff, L. (2005). Relationships between family and parent characteristics and functional abilities in children with recurrent pain syndromes: An investigation of moderating effects on the pathway from pain to disability. *Journal of Pediatric Psychology, 30*, 698-707.

Manne, S., DuHamel, K., Ostroff, J., Parsons, S., Martini, D.R., Williams, S.E., et al. (2004). Anxiety, depressive, and posttraumatic stress disorders among mothers of pediatric survivors of hematopoietic stem cell transplantation. *Pediatrics, 113*, 1700-1708.

Martin, S.C., Wolters, P.L., Klaas, P.A., Perez, L., & Wood, L.V. (2004). Coping styles among families of children with HIV infection. *AIDS Care, 16,* 283-292.

McClellan, C.B. & Cohen, L.L. (2007). Family functioning in children with chronic illness compared with healthy controls: A critical review. *Journal of Pediatrics, 150,* 221-223,

McConville, B.J., Steichen-Asch, P., Harris, R., Neudorf, S., Sambrano, J., Lampkin, B., et al. (1990). Pediatric bone marrow transplants: psychological aspects. *Canadian Journal of Psychiatry, 35,* 769-775.

Mellins, C.A., Brackis-Cott, E., Dolezal, C., & Abrams, E.J. (2004). The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Pediatric Infectious Disease Journal, 23*, 1035-1041.

Mintzer, L.L., Castaneda, M., Mesrkhani, V., Stuber, M.L., Seacord, D., & Glover, D. (2005). Traumatic stress symptoms in adolescent organ transplant recipients. *Pediatrics, 115,* 1640-1644.

Mitchell, M.J., Lemanek, K., Palermo, T.M., Crosby, L.E., Nichols, A, & Powers, S.W. (2007). Parent perspectives on pain management, coping, and family functioning in pediatric sickle cell disease. *Clinical Pediatrics, 46,* 311-319.

Murphy, D.A., Durako, S.J., Moscicki, A.B., Vermund, S.H., Ma, Y., Schwarz, D.F., et al. (2001). No change in health risk behaviors over time among HIV infected adolescents in care: role of psychological distress. *Journal of Adolescent Health, 29,* S57-63.

National Traumatic Stress Network (2005). *Understanding Child Traumatic Stress*. Retrieved August 25, 2006, from http://www.nctsn.org/nctsn_assets/pdfs/edu_materials/ Understanding_ Child_Traumatic_Stress_Brochure_9-29-05.pdf.

Newacheck, P.W. & Halfon, N. (1998). Prevalence and impact of disabling chronic conditions in childhood. *American Journal of Public Health, 88*, 610-617.

Newacheck, P.W., McManus, M.A., & Fox, H.B. (1991). Prevalence and impact of chronic illness among adolescents. *American Journal of Diseases of Children, 145*, 1367-1373.

Noll, R.B., Reiter-Purtill, J., Vannatta, K., Gerhardt, C.A., & Short, A. (2007). Peer relationships and emotional well-being of children with sickle cell disease: a controlled replication. *Child Neuropsychology, 13*, 173-187.

Nuss, S.L. & Wilson, M.E. (2007). Health-related quality of life following hematopoietic stem cell transplant during childhood. *Journal of Pediatric Oncology Nursing, 24*, 106-115.

Olley, B.O., Zeier, M.D., Seedat, S., & Stein, D.J. (2005). Post-traumatic stress disorder among recently diagnosed patients with HIV/AIDS in South Africa. *AIDS Care, 17*, 550-557.

Osterberg L. & Blaschke T. (2005). Adherence to medication. *New England Journal of Medicine, 353*, 487-497.

Pai, A.L., Greenley, R.N., Lewandowski, A., Drotar, D., Youngstrom, E., Peterson, C.C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology, 21, 407-415.*

Panepinto, J.A., O'Mahar, K.M., DeBaun, M.R., Loberiza, F.R., & Scott, J.P. (2005). Health-related quality of life in children with sickle cell disease: child and parent perception. *British Journal of Haematology, 130*, 437-444.

Phipps, S., Dunavant, M., Lensing, S., & Rai, S.N. (2005). Psychosocial predictors of distress in parents of children undergoing stem cell or bone marrow transplantation. *Journal of Pediatric Psychology, 30,* 139-153.

Phipps, S., Long, A., Hudson, M., & Rai, S.N. (2005). Symptoms of post-traumatic stress in children with cancer and their parents: effects of informant and time from diagnosis. *Pediatric Blood Cancer, 45*,952-9.

Plante, W.A., Lobato, D., & Engel, R. (2001). Review of group interventions for pediatric chronic conditions. *Journal of Pediatric Psychology, 26*, 435-453.

Radcliffe, J., Fleisher, C.L., Hawkins, L.A., Tanney, M., Kassam-Adams, N., Ambrose, C., et al. (2007). Posttraumatic stress and trauma history in adolescents and young adults with HIV. *AIDS Patient Care STDS, 21*, 501-508.

Ridenour, T.A., Daley, J.G., & Reich, W. (1999). Factor analyses of the family assessment device. *Family Process, 38*, 497-510.

Rodrigue, J.R., MacNaughton, K., Hoffman, R.G., Graham-Pole, J., Andres, J.M., Novak, D.A., et al. (1996). Perceptions of parenting stress and family relations by fathers of children evaluated for organ transplantation. *Psychological Reports, 79*, 723-727.

Rodrigue, J.R., MacNaughton, K., Hoffman, R.G., Graham-Pole, J., Andres, J.M., Novak, D.A., et al. (1997). Transplantation in children: A longitudinal assessment of mother's stress, coping, and perceptions of family functioning. *Psychosomatics, 38*, 478-486.

Rodriguez, N., Steinberg, A., & Pynoos, R.S. (1998). *UCLA Post Traumatic Stress Disorder Reaction Index for DSM-IV, Child, Adolescent, and Parent Versions*. Los Angeles: University of California at Los Angeles.

Rotheram-Borus, M.J., Lee, M., Leonard, N., Lin, Y.Y., Franzke, L., Turner, E., et al. (2003). Four-year behavioral outcomes of an intervention for parents living with HIV and their adolescent children. *AIDS, 17*, 1217-1225.

Rotheram-Borus, M.J., Lee, M., Lin, Y.Y., & Lester, P. (2004). Six-year intervention outcomes for adolescent children of parents with the human immunodeficiency virus. *Archives of Pediatric and Adolescent Medicine, 158*, 742-748.

Rourke, M.T., Stuber, M.L., Hobbie, W.L., & Kazak A.E. (1999). Posttraumatic stress disorder: understanding the psychosocial impact of surviving childhood cancer into young adulthood. *Journal of Pediatric Oncology Nursing, 16*, 126-135.

Russell, K.M., Hudson, M., Long, A., & Phipps, S. (2006). Assessment of health-related quality of life in children with cancer: consistency and agreement between parent and child reports. *Cancer, 106*, 2267-2274.

Ryan, C.E., Epstein, N.B., Keitner, G.I., Miller, I.W., & Bishop, D.S. (2005). *Evaluating and Treating Families: The McMaster Approach.* New York: Routledge.

Scheeringa, M.S., Wright, M.J., Hunt, J.P., & Zeanah, C.H. (2006). Factors affecting the diagnosis and prediction of PTSD symptomatology in children and adolescents. *American Journal of Psychiatry, 163*, 644-651.

Schreier, H., Ladakakos, C., Morabito, D., Chapman, L., & Knudson, M.M. (2005). Posttraumatic stress symptoms in children after mild to moderate pediatric trauma: a longitudinal examination of symptom prevalence, correlates, and parent-child symptom reporting. *Journal of Trauma, 58,* 353-563.

Shemesh, E., Annunziato, R.A., Shneider, B.L., Newcorn, J.H., Warshaw, J.K., Dugan, C.A., et al. (2005). Parents and clinicians underestimate distress and depression in children who had a transplant. *Pediatric Transplantation, 9*, 673-679.

Shemesh, E., Lurie, S., Stuber, M.L., Emre, S., Patel, Y., Vohra, P., et al. (2000). A pilot study of posttraumatic stress and nonadherence in pediatric liver transplant recipients. *Pediatrics, 105*, E29.

Shemesh, E., Newcorn, J.H., Rockmore, L., Shneider, B.L., Emre, S., Gelb, B.D., et al. (2005). Comparison of parent and child reports of emotional trauma symptoms in pediatric outpatient settings. *Pediatrics, 115*, e582-589.

Sherwen, L.N. & Boland, M. (1994). Overview of psychosocial research concerning pediatric human immunodeficiency virus infection. *Journal of Developmental and Behavioral Pediatrics, 15,* S5-S11.

Smith, B.A. & Shuchman, M. (2005). Problem of nonadherence in chronically ill adolescents: Strategies for assessment and intervention. *Current Opinion in Pediatrics, 17,* 613-618.

SPSS Inc. (2007). SPSS 15.0 for Windows, Rel. 15.0.1.1. Chicago: SPSS Inc.

Steele, R., Nelson, T.D., & Cole, B.P. (2007). Psychosocial functioning of children with AIDS and HIV infection: Review of the literature from a socioecological framework. *Journal of Developmental & Behavioral Pediatrics, 28*, 58-69.

Stein, R.E. & Jessop, D.J. (1984). Relationship between health status and psychological adjustment among children with chronic conditions. *Pediatrics, 73*, 169.

Stein, R.E., Westbrook, L.E., & Silver, E.J. (1998). Comparison of adjustment of school-age children with and without chronic conditions: results from community-based samples. *Journal of Developmental and Behavioral Pediatrics, 19*, 267-272.

Steinberg, A.M., Brymer, M.J., Decker, K.B., Pynoos, R.S. (2004). The University of California at Los Angeles Posttraumatic Stress Disorder Reaction Index. *Current Psychiatry Reports, 6*, 96-100.

Streisand, R.M. & Tercyak, K.P. (1995). Evaluating the pediatric transplant: General considerations. In M.C. Roberts (Ed.), *Handbook of Pediatric Psychology, Second Edition.* (pp. 71-92). New York: The Guilford Press.

Storch, E.A., Heidgerken, A.D., Geffken, G.R., Lewin, A.B., Ohleyer, V., Freddo, M., et al. (2006). Bullying, regimen self-management, and metabolic control in youth with type I diabetes. *The Journal of Pediatrics, 148*, 784-787.

Stuber, M.L., Schneider, S., Kassam-Adams, N., Kazak, A.E., & Saxe, G. (2006). The medical traumatic stress toolkit. *CNS Spectrum, 11*, 137-142

Stuber, M.L., Shemesh, E., & Saxe, G.N. (2003). Posttraumatic stress responses in children with life-threatening illnesses. *Child and Adolescent Psychiatric Clinics of North America, 12,* 195-209.

Taylor, R., Franck, L.S., Gibson, F., & Dhawan, A. (2005a). A critical review of the health-related quality of life of children and adolescents after liver transplantation. *Liver Transplantation and Surgery, 11,* 51-60.

Taylor, R., Franck, L.S., Gibson, F., & Dhawan, A. (2005b). Liver transplantation in children: Part 2 – long-term issues. *Journal of Child Health Care, 9*, 274-287.

Thompson, R.J., Armstrong, F.D., Link, C.L., Pegelow, C.H., Moser, F., & Wang, W.C. (2003). A prospective study of the relationship over time of behavior problems, intellectual functioning, and family functioning in children with sickle cell disease: A report from the cooperative study of sickle cell disease. *Journal of Pediatric Psychology, 28*, 59-65.

Todaro, J.R., Fennel, E.B., Sears, S.F., Rodrique, J.R., & Roche, A.K. (2000). Review: Cognitive and psychological outcomes in pediatric heart transplantation. *Journal of Pediatric Psychology, 25*, 567-576.

Tredger, J.M., Brown, N.W., & Dhawan, A. (2006). Immunosuppression in pediatric solid organ transplantation: opportunities, risks, and management. *Pediatric Transplantation, 10*, 879-892.

van Dyck, P.C., Kogan, M.D., McPherson, M.G., Weissman, G.R., & Newacheck, P.W. (2004). Prevalence and characteristics of children with special health care needs. *Archives of Pediatric and Adolescent Medicine, 158*, 884-890.

Varni, J., Burwinkle, T., Jacobs, J., Gottschalk, M., Kaufman, F., & Jones, K. (2003). The PedsQL in type 1 and type 2 diabetes: Reliability and validity of the pediatric quality of life inventory generic core scales and type 1 diabetes module. *Diabetes Care, 26*, 631-637.

Varni, J.W., Burwinkle, T.M., & Katz, E.R. (2004). The PedsQL in pediatric cancer pain: a prospective longitudinal analysis of pain and emotional distress. *Journal of Developmental and Behavioral Pediatrics, 25*, 239-246.

Varni, J.W., Burwinkle, T.M., Rapoff, M.A., Kamps, J.L., & Olson, N. (2004). The PedsQL in pediatric asthma: reliability and validity of the pediatric quality of life inventory generic core scales and asthma module. *Journal of Behavioral Medicine, 27*, 297-318.

Varni, J., Burwinkle, T., Seid, M., & Skarr, D. (2003). The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambulatory Pediatrics, 3*, 329-341.

Varni, J.W., Limbers, C.A., & Burwinkle, T.M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic core scales. *Health and Quality of Life Outcomes, 16*, 5:43.

Varni, J.W., Seid, M., & Kurtin, P.S. (2001). PedsQL 4.0: reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*, 800-812.

Walker, A.M., Harris, G., Baker, A., Kelly, D., & Houghton, J. (1999). Posttraumatic stress responses following liver transplantation in older children. *Journal of Child Psychology and Psychiatry, 40,* 363-374.

Walker, L.S. & Greene, J.W. (1991). The functional disability inventory: measuring a neglected dimension of child health status. *Journal of Pediatric Psychology, 16*, 39-58.

Weiss, D. & Marmar, C. (1997). The Impact of Event Scale -Revised. In J. Wilson & T. Keane (Eds), *Assessing psychological trauma and PTSD*. New York: Guildford.

Wethers, D.L. (2000). Sickle cell disease in childhood: Part II. Diagnosis and treatment of major complications and recent advances in treatment. *American Family Physician, 62*, 1309-1314.

Wiebe, D.J., Berg, C.A., Korbel, C., Palmer, D.L., Beveridge, R.M., Upchurch, R., et al. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology, 30*, 167-178.

Wiegner, S. & Donders, J. (2000). Predictors of parental distress after congenital disabilities. *Journal of Developmental and Behavioral Pediatrics, 21*, 271-277.

Wiener, L., Mellins, C., Marhefka, S., & Battles, H. (2007). Disclosure of an HIV diagnosis to children: History, current research, and future directions. *Journal of Developmental & Behavioral Pediatrics, 28*, 155-166.

Wiener, L.S., Vasquez, M.J., & Battles, H.B. (2001). Brief report: fathering a child living with HIV/AIDS: psychosocial adjustment and parenting stress. *Journal of Pediatric Psychology, 26*, 353-358.

Williams, J., Wake, M., Hesketh, K., Maher, E., & Waters, E. (2005). Health-related quality of life of overweight and obese children. *Journal of the American Medical Association, 293*, 70-76.

Winnick, S., Lucas, D. O., Hartman, A. L., & Toll, D. (2005). How do you improve compliance? *Pediatrics, 115*, e718-724.

World Health Organization (2005). AIDS cases reported to WHO - 1979-1999. *Report on the Global HIV/AIDS Epidemic*. UNAIDS/CO.13E.

Yeni, P.G., Hammer, S.M., Carpenter, C.C., Cooper, D.A., Fischl, M.A., Gatell, J.M., et al. (2002). Antiretroviral treatment for adult HIV infection in 2002: Updated recommendations of the International AIDS Society-USA Panel. *Journal of the American Medical Association, 10*, 222-235.

Young, G.S., Mintzer, L.L., Seacord, D., Castaneda M., Mesrkhani, V., & Stuber, M.L. (2003). Symptoms of posttraumatic stress disorder in parents of transplant recipients: Incidence, severity, and related factors. *Pediatrics, 111*, 725-731.

Zeller, M.H., Roehrig, H.R., Modi, A.C., Daniels, S.R., & Inge, T.H. (2006). Health-related quality of life and depressive symptoms in adolescents with extreme obesity presenting for bariatric surgery. *Pediatrics, 117*, 1155-1161.

BIOGRAPHICAL SKETCH

Lisa Ingerski received her bachelor's degree, with distinction, in psychology from the University of Virginia in 2003. She received her master's degree in clinical psychology from the University of Florida in 2005 and completed her pre-doctoral internship at Cincinnati Children's Hospital and Medical Center in 2008.